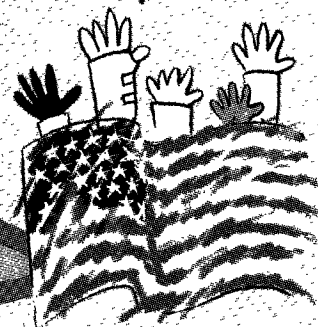


Parents Speak Out for America's Children

Report of the Surgeon General's Conference

HEALTHY CHILDREN



Ready to Learn

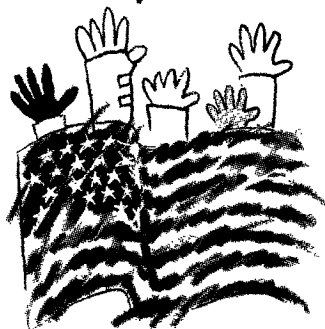
**The Critical Role
of Parents**

Policy Information Center
DHHS, Rm. 438-F HHH Bldg.
200 Indep. Ave., S.W.
Washington, D.C. 20201

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--- Ready to Learn ---

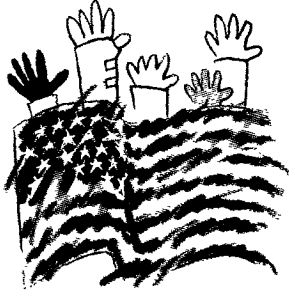
**The Critical Role
of Parents**

February 9-12, 1992

Policy and Program Development
DHHS, HHS, 85
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FEDERAL COSPONSORS

HEALTHY CHILDREN



Ready to Learn

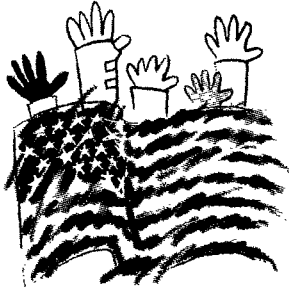
- ★ **Administration for Children and Families**, U.S. Department of Health and Human Services
- ★ **Food and Nutrition Service**, U.S. Department of Agriculture
- ★ **Office of Elementary and Secondary Education**, U.S. Department of Education
- ★ **Health Care Financing Administration**, Department of Health and Human Services
 - ★ Intergovernmental Affairs Office
- ★ **U.S. Public Health Service**, Department of Health and Human Services
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- ★ American Dietetic Association
- ★ American Medical Association
- ★ American Nurses' Association
- ★ American Public Health Association
- ★ American Public Welfare Association
- ★ American Red Cross
- ★ American School Food Service Association
- ★ Association for the Care of Children's Health
- ★ Association of Maternal and Child Health Programs
- ★ Association of State and Territorial Dental Directors
- ★ Association of State and Territorial Health Officials
- ★ Child Welfare League of America, Inc.
- ★ Children's Action Network
- ★ Federation for Children with Special Needs
- ★ General Federation of Women's Clubs
- ★ Girl Scouts of the U.S.A.
- ★ Healthy Mothers/Healthy Babies Coalition
- ★ Home and School Institute
- ★ Institute for Educational Leadership
- ★ La Leche League International
- ★ March of Dimes Birth Defects Foundation
- ★ National Association of Community Health Centers, Inc.
- ★ National Association of Elementary School Principals
- ★ National Association of Pediatric Nurse Associates and Practitioners
- ★ National Association of Social Workers
- ★ National Association of WIC Directors
- ★ National Center for Clinical Infant Programs
- ★ National Center for Educational Statistics
- ★ National Commission to Prevent Infant Mortality
- ★ National Congress of American Indians
- ★ National Dental Association
- ★ National Head Start Association
- ★ National Health/Education Consortium
- ★ National Mental Health Association
- ★ National Parent Network on Disabilities
- ★ National Parent-Teachers Association
- ★ National SAFE KIDS Campaign
- ★ National Urban League
- ★ Parent Action
- ★ Parents as Teachers National Center
- ★ Society for Nutrition Education
- ★ United Way of America

Dedication

HEALTHY CHILDREN



Ready to Learn

**The Critical Role
of Parents**

There are 64 million children in this country. When I was appointed to be Surgeon General, I vowed to speak for all of them—whether rich or poor, healthy or sick, whatever their race or ethnic background. To this end, nearly 2 years ago, I established the Healthy Children Ready to Learn Initiative. This Initiative, which focuses on the health aspects of school readiness, was born out of the President's first National Education Goal, that "By the year 2000, all children in America will start school ready to learn."

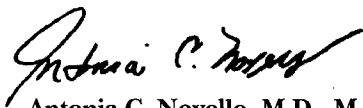
As part of this Initiative, the Conference on Healthy Children Ready to Learn: The Critical Role of Parents was held here in Washington, DC, in February 1992. More than 700 people attended—health professionals and administrators, teachers, Government officials, and others involved in the health and well-being of our Nation's young people—but our guests of honor for this Conference were the approximately 225 parents who attended from each of the 50 States, the District of Columbia, and the U.S. Territories.

Over the course of those 3 days, our time was spent listening to and learning from one another. We learned what worked; we were told what didn't. The Conference was unique in that the parents spoke from their hearts. They raised a collective voice that said, in effect, "As parents, we must stand up for our children and our families and see that our needs are met. We must do so with dignity, and we must demand respect when others try to rob us of our dignity." Parents who never knew that they could speak for others eloquently articulated the needs of children and families. Although these parents came to our Conference from all parts of the country and from all walks of life, they came with the same mission: to improve the lives of the children and the families of this country.

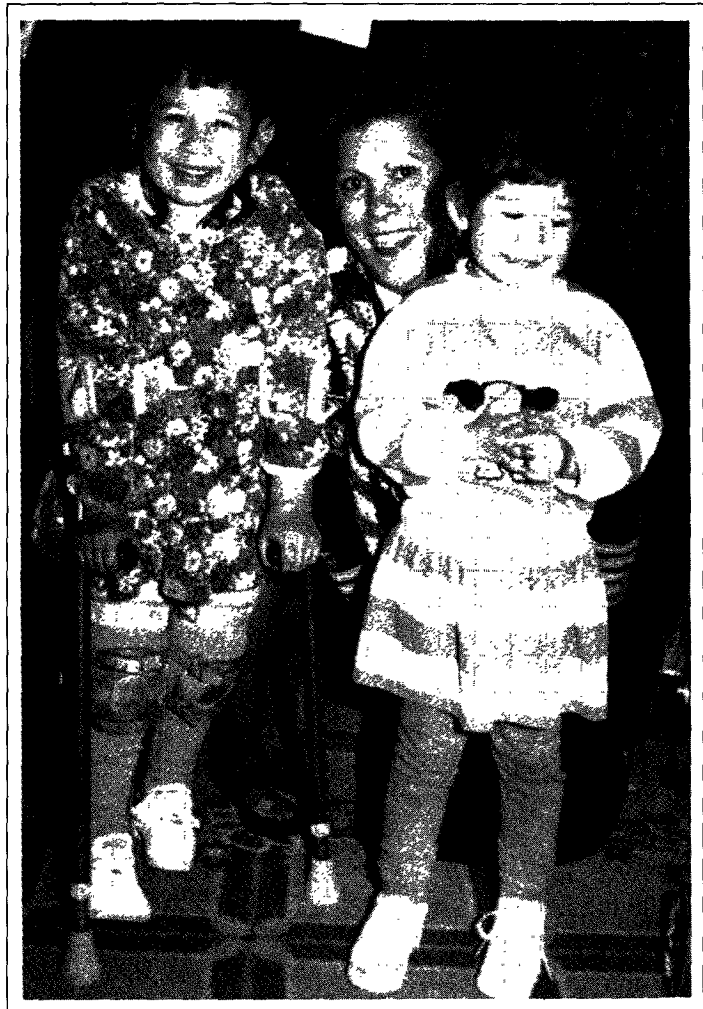
This proceedings document is dedicated to those parents who attended our Conference. We are proud of them and inspired by them. It is our sincere hope that what we learned in those 3 days is reflected honestly in these pages. This document will serve as a "guide" for the rest of us and as an inspiration to do what was asked. As I stated at the close of our Conference, "This Conference may be ending, but what we have accomplished is the beginning of a way of acting and thinking with families in mind."

We must care for our children. That responsibility does not belong to only one individual or entity or Government agency. What we learned at this Conference is that we are all responsible for all of the children. We must become advocates for one another and share our strengths. When President Bush outlined his six National Education Goals, he envisioned an America where our children can compete on an international level. He knew that the children of today are the explorers, the writers, the teachers, and the inventors of tomorrow. If we invest in their future today, we can ensure their growth and advancement for tomorrow.

As Surgeon General, I will speak for you, the families of America. My voice and my office are at your service. I thank you from the bottom of my heart for your thoughts, your energies, and your heartfelt spirit.



Antonia C. Novello, M.D., M.P.H.
Surgeon General

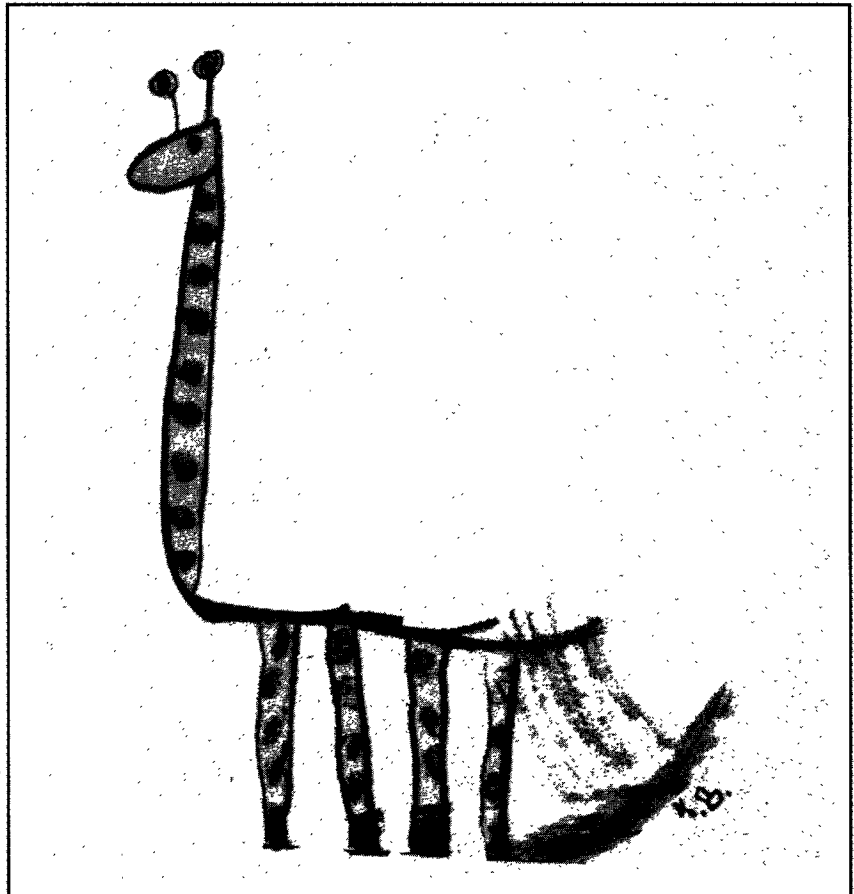


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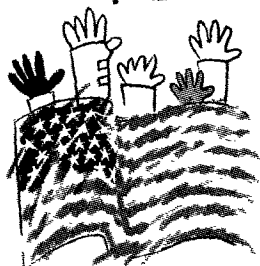
Executive Summary



Executive Summary

Introduction

HEALTHY CHILDREN



--- Ready to Learn ---

On February 9-12, 1992, in Washington, DC, Surgeon General Antonia Novello hosted the “Healthy Children Ready to Learn: The Critical Role of Parents” Conference, sponsored jointly by the National Governors’ Association, the Department of Health and Human Services, the Department of Education, and the Department of Agriculture. The 3-day Conference was part of the Surgeon General’s Healthy Children Ready to Learn Initiative, developed in support of the first of six National Education Goals established by President George Bush and our Nation’s Governors in February 1990. This goal states, “By the year 2000, all children in America will start school ready to learn.”

At the Conference, approximately 225 parents, representing the 50 States, the District of Columbia, and the U.S. Territories, joined with more than 500 government officials and representatives from public and private health, education, and social service agencies to search for new ways to advance the health and education of America’s children. The parents were selected by their States and Territories to represent their area’s economic, social, and cultural diversity. Parents from diverse backgrounds and other participants directed their efforts toward these challenging goals:

- ★ To identify the strengths of parents and families in their roles in preparing children to be healthy and ready to learn.
- ★ To voice parent and family needs to the health, education, and social service professionals responsible for programs that address the goal of preparing children to be healthy and ready to learn.
- ★ To highlight Federal, State, and community-based programs that effectively address these needs.
- ★ To identify cross-cutting public/private/voluntary strategies that build a parent-and-family/professional partnership within the scope of existing programs.

“By the year 2000, all children in America will start school ready to learn.”



Conference Structure

During the Conference, the State Parent Delegates attended Parent Work Groups to discuss three phases of involvement in health, education, and social service systems (the patchwork of health, education, and social service programs and activities throughout our Nation): awareness of and entry into the systems, participation in the systems, and transition as families move through the systems. The delegates were grouped into Parent Work Groups by regions, and special Work Groups were established for Native Americans and Migrant families to ensure that their issues were not lost. (The Native Americans and Migrant families were also represented in the Regional Work Groups.)

At the close of the Conference, three representatives from the Parent Work Groups (one for each stage discussed, i.e., awareness and entry, participation, and transition) reported their findings to the Conference at large. The issues they raised were addressed by a panel of Government officials, directors of Federal programs that administer key health, education, and social service programs.

As the State Parent Delegate Work Groups were meeting, other participants attended presentations by panels of professionals and parent advocates involved with health, education, and social service systems. The focus of these presentations was on how to make programs fit families, instead of making families fit the programs. The following topics were covered in the panel presentations: (1) Early Childhood Issues That Affect School Readiness and Health; (2) Helping Families Get Services: Some New Approaches; (3) Healthy Children Ready to Learn: What Are the Roles of Parents, Educators, Health Professionals, and the Community? (4) Special Issues That Impact Children and Families: Substance Abuse, Human Immunodeficiency Virus (HIV), and Violence; (5) Disabilities; (6) Exploring Comprehensive Health and Education Models for Young Children; (7) Children with Special Health Care Needs: Lessons Learned; (8)

Parenting: The Critical Role; (9) Childcare: Two Perspectives; and (10) Healthy Start, Head Start, Even Start, and the Supplemental Food Program for Women, Infants, and Children (WIC): Integrating Health, Education, and Social Service Programs.

Over the course of the 3 days, President George Bush and members of his Cabinet expressed their commitment to the Surgeon General's Healthy Children Ready to Learn Initiative by addressing the Conference participants. President Bush, Secretary of Health and Human Services Louis Sullivan, Secretary of Agriculture Edward Madigan, and Secretary of Education Lamar Alexander each described the efforts of the Administration in meeting the first National Education Goal.

The Conference also provided 28 workshops covering a variety of health, education, and social topics from which the participants could choose. During the breaks, a special exhibition containing information about Federal, State, and community programs concerned with the health, education, and well-being of children was open to Conference participants. Also during the breaks and before the opening session, the Conference featured entertainment provided primarily by local children's groups.

Charge to the Participants

As Surgeon General, Dr. Novello is responsible for the health of our Nation's people, and as a pediatrician, she is most passionately concerned about her responsibility to our Nation's children. Therefore, Dr. Novello has made the health of our Nation's children the cornerstone of her agenda. In her Charge to the Conference, Dr. Novello stated that the first National Education Goal holds special importance for her. "Health and education go hand in hand; one cannot exist without the other," she said. "To believe any differently is to hamper progress." She cited the three specific objectives in the comprehensive goals statement for the first National Education Goal:

- ★ All disadvantaged and disabled children will have access to high-quality and developmentally appropriate preschool programs that help children prepare for school.
- ★ Every parent in this country will be their child's first teacher and devote time each day helping his or her preschool child learn; that parents will have access to the training and support they need.
- ★ Children will receive the nutrition and health care needed to arrive at school with healthy minds and bodies, and the number of low-birth weight babies will be significantly reduced through enhanced prenatal health systems.

Dr. Novello spoke about some of the barriers that our country faces in developing healthy children ready to learn: failure to immunize against childhood diseases, Acquired Immunodeficiency Syndrome (AIDS), childhood injuries, and violence. She stated that, although the statistics are staggering, she is hopeful that we can make a difference. She announced her commitment to the arduous task and challenged the Conference participants: "I see our task as improving the health and welfare of our Nation's children in every way we can." She urged the participants to work together, to teach and to learn from one another. "When it comes to health and education," she said, "we need total intuitive conviction to remove every barrier and reach every child." She urged the parents and professionals present to help make the Conference "a blueprint for bonding education and health—an essential task, if our children are to succeed."

Parent Work Groups

In their discussions of the stages of involvement with health, education, and social service systems (awareness and entry, participation, and transition), the parents examined three main questions related to the different stages:

- ★ What is my role as a parent?
- ★ What are the barriers and issues of concern?
- ★ What are some solutions and existing model programs incorporating those solutions?

Several issues and themes recurred in the parents' discussions, forming a kind of national consensus on the issues among the parents. The conclusions from this national consensus follow.

Awareness of and Entry into Health, Education, and Social Service Systems

Roles and Responsibilities of Parents

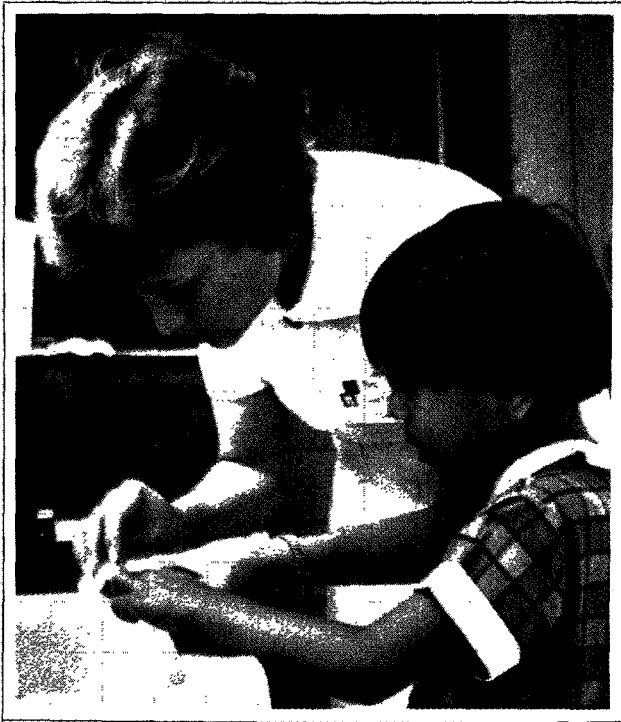
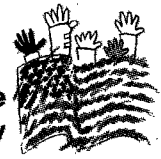
First parents must identify their children's needs. Then, they must find the programs offering services that meet those needs. They should consider themselves full partners with the professionals in making decisions for their children. Parents should be advocates and should network with other parents to share information and moral support.

Barriers to Awareness and Entry

Information about the full range of programs available to families is not readily accessible. In addition, the bureaucracy devoted to administering most programs is daunting to most parents. The paperwork is overwhelming, both in volume and in language. Eligibility criteria are inflexible. Social service workers, who often suffer from employee burnout or are culturally insensitive, can be patronizing and intimidating. Inflexible office hours and difficulties with transportation add to the problem. The systems seem to suffer from a lack of accountability. Parents feel frustrated and do not know where to turn for help.

Solutions

An easy-to-read, universal application form for all services was a major proposal, along with consistent, flexible eligibility criteria. Agencies should operate during hours that are more convenient to working parents. Programs should be instituted in elementary schools to



develop social competency and effective parenting skills. Funds should be made available for support groups. Parents need a way to talk back to the systems. A campaign should be conducted to increase public awareness of the importance of healthy children.

Participation in Health, Education, and Social Service Systems

Roles and Responsibilities of Parents

The parents' primary role is to nurture their children. They should also serve as role models not only to their children but also to other families who need service, and they should enlist those families into programs. Parents need to be fully involved partners with the service providers—in making care decisions, communicating cultural sensitivities, and evaluating services.

Barriers to Participation

The same difficulties exist here as with gaining access to the system: paperwork, inflexible hours, transportation problems, and gaps in service. These problems seem to stem principally from a lack of coordination among programs and the absence of a family-centered

philosophy. Again, the parents saw a need for family support groups and funding to organize them.

Solutions

First, training in parent skills should begin early. Improved communications among agencies would solve many problems. "One-stop shopping" (i.e., receiving a multitude of services at a convenient location) with flexible hours and simplified paperwork would go a long way toward easing parents' burdens. A directory of services also would be helpful. Consistent funding for programs and parent involvement on the boards overseeing programs would help provide quality service. A "national psychology" that supports families should be encouraged; i.e., our society must be encouraged to value the family and support the efforts of parents in raising their children, particularly for families who need help. To that end, people should vote for candidates who espouse that view and who will work to further it when elected.

Transitions Through Health, Education, and Social Service Systems

Roles and Responsibilities of Parents

Parents need to be active participants in transitions from program to program because they are the best evaluators of their children's needs. They must be prepared for and remain involved in the transition process and, in turn, prepare their children. Again, they should be advocates for the child to ensure that the child is truly getting what he or she needs. Other important aspects of the parents' role are loving their children and helping develop self-esteem for themselves and for their children. For smoother transitions, parents must also be good recordkeepers and request written reports.

Barriers to Smooth Transitions

A lack of communication among agencies regarding available services complicates the transition process for families. Reports that are not written in the language of the parents make transitions confusing. Culturally

insensitive service workers isolate parents. Unstable funding makes it difficult to predict the availability of a particular program when a transition occurs.

Solutions

Improved communications was one of the most often-cited needs, along with information clearinghouses, hotlines, service directories, support groups, and community outreach. Service providers should receive sensitivity training. Once again, the parents cited the need for a streamlined system for handling paperwork, one-stop shopping, and sensible hours.

Characteristics of Programs Parents Grade A+

Parents said that programs must have the following characteristics: be child centered and family friendly, be easily accessible, have broad eligibility standards, be antidiscriminatory and multilingual, be well-promoted, provide individualized service, be staffed sufficiently, and be open at convenient hours. In addition to having these characteristics, programs must coordinate with one another to facilitate entry and participation in the systems and to avoid duplication or gaps in services. Above all, programs should empower families as they serve them. The parents strongly recommended programs that involve parents directly as a way to empower them. Furthermore, they stressed that programs should involve the parents in making the decisions that affect their children, decisions ranging from policies to staffing and budgets.

Parent Presentations

On the final day of the conference, three representatives from the Parent Work Groups summarized their conclusions. One representative focused on the discussions of awareness of and entry into health, education, and social service systems, another on participation, and the third on transitions.

Awareness of and Entry into Health, Education, and Social Service Systems

Sherlita Reeves

Parent Delegate from Arkansas

In summarizing the reports from the groups on awareness and entry, Ms. Reeves said that the parents' roles and responsibilities should include becoming informed about their own child's needs, acting as an advocate for the child, meeting their own needs so that they can be equal partners with service providers and professionals, and networking with other parents.

The issues of concern were too much paperwork, difficulty in getting into the system, materials not written in parents' language, and providers who do not understand the culture of those that they serve. Inflexible hours of operation, lack of transportation, and environmental barriers for physically impaired people were noted as barriers. A significant problem is the lack of accountability in the systems.

Solutions to these problems focused on establishing school-based programs that develop social competencies, building support networks within the community, producing directories of resources with toll-free numbers, designing one-stop shopping for all mandated programs, creating a universal application form, and giving parents a way to talk back to the system.

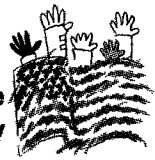
Participation in Health, Education, and Social Service Systems

Ellie Valdez-Honeyman

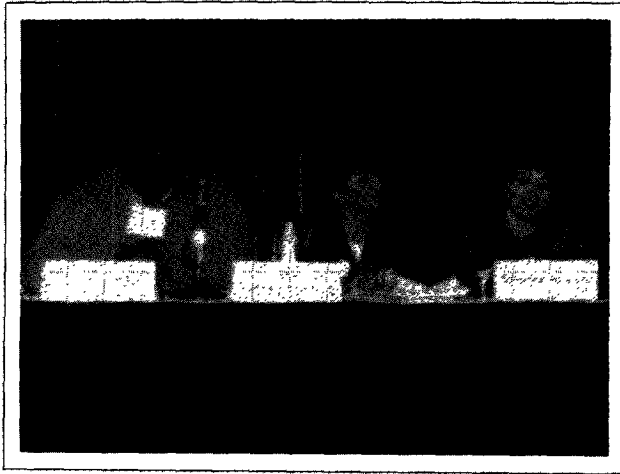
Parent Delegate from Colorado

Ms. Valdez-Honeyman stated that parents need to provide for the needs of their children. Food, clothing, safety, health care, and quality time are essential, but parents also need to instill a spirituality that encourages values, morals, and respect for themselves and for others.

As families begin to participate in the systems, just as when they are entering the systems, parents need to continue to be advocates—for their own children, for other families, and for components of the systems that work for them. They should be involved in their communities.



HEALTHY CHILDREN Ready to Learn



Ms. Valdez-Honeyman related other areas of concern identified by the parents. They felt that a stigma is attached to receiving services, the stigma of being poor. Eligibility criteria can also be a problem because they are not flexible enough to include all who have need. Also, language not native to the parents and system jargon make dealing with the systems confusing. Transportation is an issue in rural areas where services are limited and parents must travel long distances. Programs often do not have convenient locations or hours for obtaining services.

The solutions identified by the parents fell into two categories: local initiatives that deal with local service delivery, and Federal initiatives that reach across all levels to create a standard in which service systems welcome and embrace families. The principles would then be embodied in the design, delivery, and evaluation of services.

Transitions Through Health, Education, and Social Service Systems

Larry Bell

Parent Delegate from Delaware

Mr. Bell provided a laundry list of issues that the parents had discussed regarding transition. First, parents need to participate in the transition process so that they can help prepare their children for the transition. They can

be better prepared for the transitions themselves if a resource manual or some form of information about new locations or programs, including contact names, were available to them before the transitions occur.

The parents acknowledged their responsibility to maintain copies of their children's records to ensure that they are not lost during transitions. The parents also have a significant responsibility in ensuring that the roles of parents and professionals in the transition process are clarified and that the family is treated with respect. Programs and staff must be culturally sensitive and relevant, and they must help develop self-esteem not only for the children but also for their parents, who then can be good role models. Parents should not be afraid to confront the systems if necessary to ease the transition process.

The parents stressed that, to ease transitions, parental involvement in programs should be consistent. Furthermore, parental involvement should include program design and policy-making decisions.

Mr. Bell also presented concerns that were raised by the other representatives. The parents cited the need for improved communication among the various systems that serve them in the transition process. Improved communication would help avoid duplication of services and promote continuity of service as transitions occur. They recommended an interstate computer network to ease the application process as families move from State to State. They urged that school credits be accepted more readily from State to State. They repeated the plea for one-stop shopping, less paperwork, flexibility of service, and help with transportation problems. They also promoted the use of school social workers who could act as advocates for parents and children in the transition process.

Finally, Mr. Bell presented the parents' recommendation for legislative action to help improve the transition process and urged the parents to elect officials who are family advocates. He summarized his remarks by reminding the participants of the three C's of successful transitions: consistency, continuity, and coordination of services.

Responder Panel

James O. Mason, M.D.

*Assistant Secretary for Health
U.S. Department of Health and Human Services*

Assistant Secretary Mason, head of the U.S. Public Health Service, answered the parents' challenge for action by the officials by promising to meet with the State and territorial health departments and their commissioners to discuss the issues raised by the parents. He reinforced the parents' contention that leadership must come from all levels.

Dr. Mason stated that he agreed with 98 percent of what the parents said and his agency is working toward creating a user friendly system of health care. As an example he offered a new Model Application Form, which is a simplified, unified, uniform application available for use in the States. He stated that both the Federal Government and the parents want the same features in the systems, but that each must work from opposite ends to achieve them at the middle levels where the programs are implemented.

He also outlined Healthy People 2000, a national program with 300 measurable health goals for the year 2000; 170 of these goals relate to mothers, infants, children, and adolescents. He closed by expressing the willingness to work together as partners.

John T. MacDonald, Ph.D.

*Assistant Secretary for Elementary and Secondary Education
U.S. Department of Education*

Assistant Secretary MacDonald said that schools need to return to things that parents and children need. He shared a vision of schools as the hub of one-stop shopping, where education is the central mission but where children and families can use other family services as well. This facility would operate from early in the morning until late at night, including weekends and during summer and holidays. It would virtually never close. He also said we need a massive urban intervention program using Federal resources in conjunction with State and local resources to provide for communities.

Assistant Secretary MacDonald explained that many current programs can help one another. He cited Even Start as an example. A program for children 0 through 7 years old that provides not only parenting and childcare but also job training and placement, Even Start can be used to buy or expand Head Start services or to create its own services. He emphasized that Federal agencies are working to integrate their services, and they will continue to do so with the support of America's families in persuading Congress to make needed changes.

Catherine Bertini

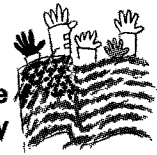
*Assistant Secretary for Food and Consumer Services
U.S. Department of Agriculture*

The Department of Agriculture spends more than half of its budget on food assistance programs for the poor and children. Ms. Bertini explained how the Department currently is working with directors around the country to promote joint services for immunization and WIC. She also described direct certification of school lunch and breakfast programs through a computer marriage of the school lists with files from the Aid to Families with Dependent Children (AFDC) program in an effort to simplify eligibility factors and expand access. The two-signature policy for Food Stamps has been eliminated and the agency has launched a pilot program called Electronic Benefit Transfer (EBT) using bank cards for the food stamp program.

In closing, Ms. Bertini discussed the importance of school breakfast for children coming to school ready

HEALTHY CHILDREN Ready to Learn





to learn. Half of the schools that have school lunch programs also have breakfast, but through expanded access the schools can feed more kids. She urged parents to work with and support the regional agencies that provide services and to help persuade Congress to support proposals for change in the systems.

Wade Horn, Ph.D.

Commissioner

*Administration for Children, Youth and Families
U.S. Department of Health and Human Services*

Dr. Horn admitted that Head Start works because it is built upon parental involvement and community support. Head Start also integrates health services and social services and is one of the largest delivery systems of health services to poor children in our country. However, Head Start still has much work to do. It is undertaking three new challenges: administering more money to serve more kids; increasing services to adults with children in Head Start, particularly adult literacy and substance abuse; and providing job training for Head Start parents.

Dr. Horn also warned that Head Start is not an inoculation against everything that can possibly go wrong in a child's community. We must do a better job of creating a good environment for children when they leave Head Start. To that end, he has been working with Assistant Secretary MacDonald to establish better connections between Head Start and our Nation's public schools.

Christine Nye

Director

Medicaid Bureau

Health Care Financing Administration

Ms. Nye described the massive effort that Medicaid makes to serve our people; it spends more than \$100 billion for services to 30 million Americans, 17 million of whom are children. She continued that, although Medicaid is expanding services and eligibility, it still falls short in many areas. However, she cited some bright spots: expansion of eligibility for children to the maximum in as many as 20 States and increased flexibility in providing waivers to

keep children with special health care needs at home rather than in institutions. One expanded program for children is the early Periodic Screening, Diagnostic and Treatment Program, the greatest child health reform since the enactment of Medicaid.

Ms. Nye also described efforts to make access to Medicaid easier: streamlining application forms, increasing payments to community health centers, and working to overcome barriers between physicians and Medicaid. She expressed her commitment to continuing these efforts, but cautioned the participants that Medicaid is administered by the States and that the parents should work with the State Medicaid staff and inform them of the findings of the Conference. In closing, she thanked the parents for rejuvenating her own commitment to implementing changes in the program.

Lou Enoff

Principal Deputy Administrator

Social Security Administration

Although most people think of Social Security as a retirement program, Mr. Enoff informed the participants that it pays more than \$1 billion to more than 3 million children under its programs every month. These children either have disabilities or they are the offspring of retired or disabled workers or deceased parents. Social Security has expanded access with a nationwide 800 number that operates 12 hours a day with bilingual help if the client needs it. In addition, Supplemental Security Income (SSI) has an outreach program to find those people who are eligible. Social Security has begun integrating services where possible with other agencies. Also, Social Security has published standards of service for its offices, which will be modified as goals in providing services are met. For instance, Social Security cards are now issued within 10 days after the application is filed; the same process formerly took up to 4 weeks.

Mr. Enoff urged the parents to call if they have a problem with or concern about Social Security. He reminded them of the 800 number and added that, if they received no satisfaction from the service providers on the toll-free line, they could call him directly at 410-965-9000.

Keynote Speeches

George H. Bush

President of the United States

The President said that, in his administration, families come first. Pointing to the critical role of parents, he said that, as a child's first teachers, they offer the love and nourishment that no government program can ever hope to provide.

Citing programs that promote the health and education of young children, President Bush stated that, since 1988, Federal dollars for immunization have more than tripled. In the last 3 years, funding for Head Start has almost doubled; this year's proposed increase of \$600 million is the largest single increase in the program's history.

President Bush also outlined the provisions of his health care reform plan: providing a \$3,750 tax credit for low-income families and an equal tax deduction for middle-income families; cutting costs to make health care more efficient; and cutting waste and abuse. The President called it a common-sense reform that will maintain high-quality care, cut costs, ensure maximum freedom of choice, and give every family access to health care.

Louis W. Sullivan, M.D.

Secretary of Health and Human Services

Secretary Sullivan said we must invest in children. To support that investment, the President's 1993 budget proposes to increase funding for programs serving children to \$100 billion. Infant mortality is a national priority, and an expansion of the Healthy Start initiative will concentrate \$143 million on 15 communities with stubbornly high infant mortality rates.

We must also focus on prevention. The President has requested \$52 million for immunization activities and \$40 million for Centers for Disease Control (CDC) Lead Poisoning Prevention Grants to support 30 state-wide programs.

Finally, we must empower parents. The President's \$600 million increase in funding for Head Start will serve an estimated 157,000 additional children in 1993

HEALTHY CHILDREN Ready to Learn



and will involve their parents. In addition, the tax provisions of the President's health care reform proposal will help more than 90 million Americans and will cover 95 percent of the uninsured.

Edward Madigan

Secretary of Agriculture

Secretary Madigan outlined the many Department of Agriculture programs that have direct impact on children. He cited the following examples: WIC, a gateway to other government services such as immunization; the Child and Adult Care Food Program, which serves meals to preschool-aged daycare children (including Head Start meals), a service that is expanding; the National School Lunch and Breakfast Programs, which are being cross-matched with AFDC files to ensure that entitled children are reached; various summer food assistance programs; Food Stamps, the largest food assistance program; and various other programs for distribution of commodities.

In addition to providing food, the Department of Agriculture also provides nutrition education through various programs. The Nutrition Education and Training

Program (NET) trains school food-service personnel, teachers, and students. The National Food Service Management Institute, which operates at the University of Mississippi, trains school-lunch operators. Also, WIC provides nutrition education as an integral part of its program. Secretary Madigan urged the participants to work locally to ensure the success of these programs.

Lamar Alexander

Secretary of Education

Secretary Alexander reiterated the Administration's commitment to Federal standards for quality education. He recounted the implementation of the Healthy Children Initiative in Tennessee during his term as Governor. That program sought to expand prenatal care, identify doctors for newborns, and encourage employers to provide childcare opportunities for their employees.

Secretary Alexander stated that, although national policies and State programs are important because they affect funding, the fundamental problem is a matter of parents, families, and communities taking care of children and putting a priority on them. He said the Department of Education now has 27 different Federal programs that are available for children under 5 or 6 years old, but the challenge is to spend the money more wisely.

As an example, Secretary Alexander pointed to the Decatur, Georgia, school district, which has turned the school community around by setting and enforcing tough standards and by using the school as the organizing point to integrate community services for the children. In closing, Secretary Alexander encouraged the audience to assist their communities in becoming part of the America 2000 program.

Roger B. Porter, Ph.D.

Assistant to the President for Economic and Domestic Policy

Dr. Porter stated that the President's commitment to the goal that all children start school ready to learn permeates his administration. The President's Education Policy Advisory Committee, which is made up of educators, business and labor leaders, and media representatives, has spent much time discussing ways to

enhance parental involvement in the health and education of our children. In addition, the President has established a partnership with the Nation's Governors in adopting the six National Education Goals.

Dr. Porter stated three convictions that synthesize the spirit of the National Education Goals. One, families come first. Two, we must never allow things that matter most to be at the mercy of things that matter least. We, as a society, must honor those activities that involve one generation transmitting to the rising generation a set of fundamental values and aspirations, which includes good health and a commitment to learning. Three, we are all in this together.

Closing Remarks

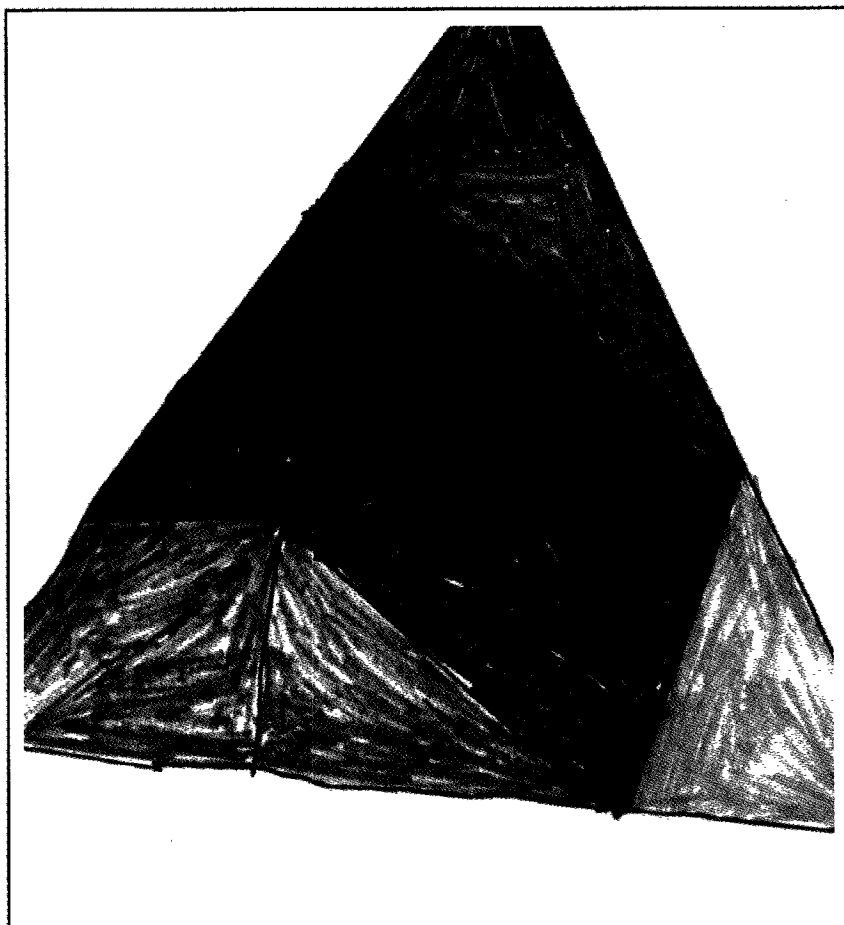
In her closing remarks, Dr. Novello observed that everyone came together at the Conference for only one purpose: to improve the lives of children and families. She said that reforms in the health, education, and social service systems of this country will be advanced through the families. It was her belief that the Conference did one thing beautifully: It vindicated parents. Parents will no longer be silent partners; they will be activists and advocates.

Dr. Novello asked attendees to join her in sharing the responsibility for making their families and children well. She reiterated some of the concerns raised at the Conference: the importance of fathers in the family, the need for flexible services and cultural sensitivity, the needs of teenage parents, and the desire for self-esteem for all of our children and their parents. She urged the participants to become involved and share with those at the local and at the State levels, in the public and in the private sectors. Our children's well-being is no longer one person's responsibility, and we must "get real." There is too much at stake.

This Conference, then, can be just the beginning of a coalition of parents trying to determine, through their collective actions, what this Government can do. In closing, Dr. Novello challenged the participants one last time. "I'm with you," she said. "Are you with me?"

Chapter 1

Introduction



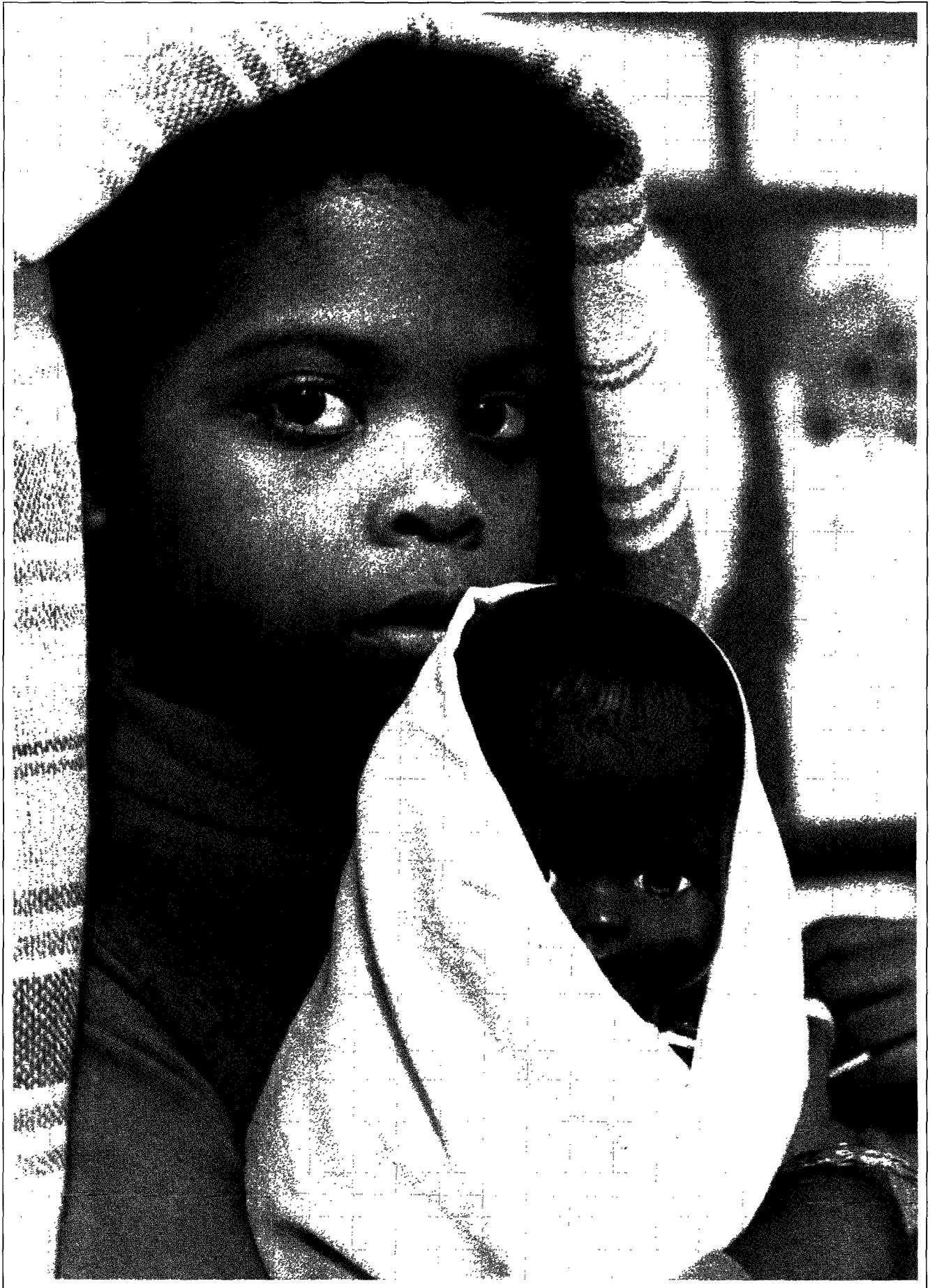
Chapter 1

Introduction



On February 9-12, 1992, at the Ramada Renaissance Techworld in Washington, DC, the Surgeon General, Dr. Antonia Novello, hosted the “Healthy Children Ready to Learn: The Critical Role of Parents” Conference. This conference was jointly sponsored by the National Governors’ Association, the Department of Health and Human Services, the Department of Education, and the Department of Agriculture. The Conference was held as part of the Surgeon General’s Healthy Children Ready to Learn Initiative, which in turn supports the first of six National Education Goals established by President George Bush and our Nation’s Governors. This goal states, “By the year 2000, all children in America will start school ready to learn.” Recognizing the crucial role of parents in ensuring their children’s good health and preparing them for school, Dr. Novello invited them to join with Government officials and representatives from public and private health, education, and social service agencies to open the channels of communication and to explore innovative steps to support the care and education of our Nation’s children more effectively. Approximately 225 parents, representing the 50 States, the District of Columbia, and the U.S. Territories, gathered with more than 500 professionals concerned about the care of children to express the needs of families and explore ways that those needs can be addressed. Appendix A lists the more than 700 participants of the Conference.

“Providing for health, nourishment, and active parenting are basic ways of providing a suitable foundation for normal growth and emotional well-being, a foundation that fosters the ability to learn and ensures school readiness.”



Background

The seeds for the Conference were planted in February 1990, when President Bush and the Nation's Governors made education a national priority and established the six National Education Goals. The first goal is an extremely important one because it focuses on the foundations of learning: physical, social, and emotional health and well-being, and cognitive development.

Providing for health, nourishment, and active parenting are basic ways of providing a suitable foundation for normal growth and emotional well-being, a foundation that fosters the ability to learn and ensures school readiness. However, deficits in any of these areas during the critical early period in a child's development are difficult, if not impossible, to overcome. To achieve the first National Education Goal, our Nation must provide access to health care and proper nutrition, education for parents, and educational programs for all of our children. In August 1990, through the announcement of her Healthy Children Ready to Learn Initiative, the Surgeon General accepted the challenge to support achievement of this readiness goal. Dr. Novello's initiative focuses on the health component of the first National Education Goal because children's ability to learn is dependent on their health.

To assist her in undertaking this challenge and to explore the best means to meet the goal, Dr. Novello formed an Advisory Group of highly qualified representatives from the White House staff and the Departments of Education, Agriculture, and Health and Human Services. (The Advisory Group members are listed in Appendix B.) The role of the Advisory Group is to recommend steps to improve the health and well-being of children so that they are healthy and ready to learn when they begin school. This role encompasses the following tasks: (1) determining the health needs of preschoolers and their parents; (2) identifying Federal resources that can be used to meet those needs; (3) discovering gaps where resources to meet the needs are

lacking; (4) clarifying the relationship between the Federal Government and the States in meeting these needs and the responsibilities of each; (5) developing strategies to minimize barriers to cooperation among Federal, State, and local agencies and private organizations involved in the health and education of young children; and (6) identifying ways to expand the Nation's resources through cooperation and collaboration to meet the challenges of this readiness goal. Among other recommendations, the Advisory Group advised seeking parents' perceptions of needs that must be met if our Nation is to reach the readiness objective.

The design of this Conference was based on the Advisory Group's recommendations. The Surgeon General set these challenging goals for the Conference:

- ★ To identify the strengths of parents and families in their roles in preparing children to be healthy and ready to learn.
- ★ To voice parent and family needs to the health, education, and social service professionals responsible for programs that address the goal of preparing children to be healthy and ready to learn.
- ★ To highlight Federal, State, and community-based programs that effectively address these needs.
- ★ To identify cross-cutting public/private/voluntary strategies that build a parent-and-family/professional partnership within the scope of existing programs.

In preparation for the Conference, the Surgeon General requested that the States identify parents who would make up a State Parent Delegation at the Conference. The term "parent" was broadly defined to include anyone who is guardian of a small child, i.e., parents, grandparents, adoptive parents, foster parents, etc. The individual State delegations were asked to hold pre-Conference meetings to discuss issues relating to health, education, and social service systems of importance to the parents.

Conference Organization

The Conference, which was the result of 18 months of planning by the Surgeon General and her Advisory Group, assisted by the Planning Committee (listed in Appendix C), provided a unique opportunity for parents and families to meet with Federal, State, community, and private professionals from health, education, and social service systems. The agenda (Appendix D) was carefully planned to make the Conference an effective forum for information exchange.

The State Parent Delegates attended three Parent Work Groups to discuss their needs and issues relating to three phases of involvement in the health, education, and social service systems: awareness of and entry into the systems, participation in the systems, and transitions as families move through the systems. The delegations were grouped according to geographical regions, and special work groups were established for Native American and Migrant families (who were also represented in the regional work groups) to ensure that their special concerns were not lost. The Facilitators and Recorders for these discussions are listed in Appendix E.

In her Charge to the Participants, found in Chapter 2, the Surgeon General emphasized that these Parent Work Groups were the focus of the Conference. Chapter 3 of these proceedings summarizes the issues discussed in the Parent Work Groups. The summaries examine a broad national consensus from issues raised in several of the work groups and then explore the narrow focus of the individual work groups. Chapter 4 contains the findings as presented to the full Conference at the closing session by three State Parent Delegate representatives. It concludes with the remarks of the Responder Panel, directors of government programs that provide services, who responded to the issues presented by the parents.

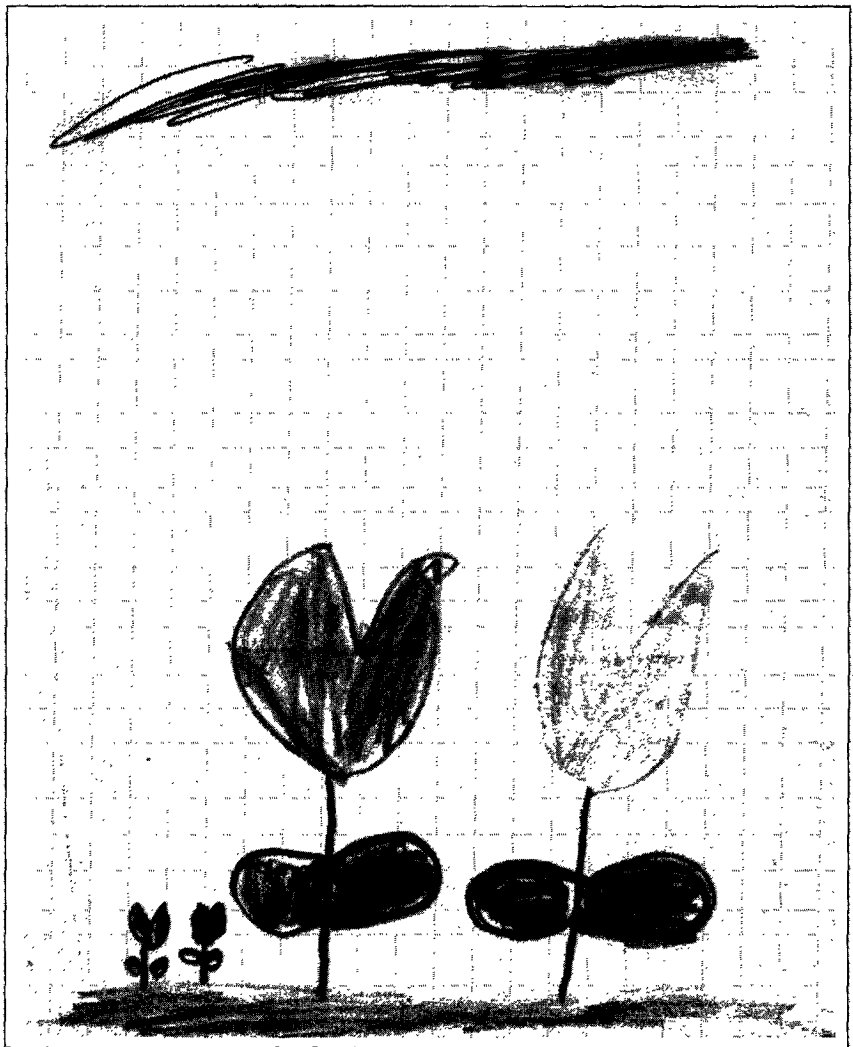
During the Conference, President Bush and key members of his Administration expressed their personal commitment to Surgeon General Novello's initiative and emphasized its importance to our Nation's future by their attendance at the Conference and their remarks to the participants. The speeches delivered at the Conference by President Bush, Secretary of Health and Human Services Louis Sullivan, Secretary of Agriculture Edward Madigan, Secretary of Education Lamar Alexander, and Assistant to the President for Economic and Policy Development Roger Porter are found in Chapter 5.

Concurrent with the Parent Work Groups, panel presentations that explored current services, both public and private, and parent support groups were conducted for General Participants (those who were not State Parent Delegates). These presentations, by panelists who were experts in their respective fields, focused on ways to customize services to fit families instead of trying to fit the families into the services. Chapter 6 contains summaries of the Panel Presentations.

All participants had a choice of 28 informative workshops covering a variety of topics from nutrition, health care, and injury prevention to violence and its impact on children. These workshops, led by professionals in the fields, are described in Appendix F. Additionally, the Conference presented a special exhibition of Federal, State, and local programs dedicated to the health and education of children. Program representatives shared information about the programs and distributed materials. Appendix G contains a listing of the exhibitors. Participants were entertained during each of the breaks by an array of performers, most of whom were children. Appendix H recognizes each group who shared their talents with the participants.

Chapter 2

Charge to the Conference



Chapter 2

Charge to the Conference

Antonia C. Novello, M.D., M.P.H.
Surgeon General

Good morning. I would like to welcome you to the "Healthy Children Ready to Learn: The Critical Role of Parents" Conference. This Conference is the culmination of 18 months of planning, outlining, and meeting with the best and brightest individuals concerned with the health and education of our Nation's children.

President George Bush has made the education of our Nation's children a major priority of his Presidency. The Department of Health and Human Services and Secretary Sullivan have made caring for children a cornerstone of the Department's agenda, and as the Surgeon General, I have made the health of our Nation's children the cornerstone of mine. Health and education go hand in hand; one cannot exist without the other. To believe any differently is to hamper progress. Just as our children have a right to receive the best education available, they have a right to be healthy. As parents, legislators, and educators, it is up to us to see that this becomes a reality.

Therefore, we are meeting to improve the education and health of our Nation's children and to improve these things through the eyes of parents, through the collective participation of the family. This is one of the most serious tasks for any society, and it should not be any less serious for all of us gathered here today.

As I welcome you and ask you to give this task your most serious attention, I am going to ask even more of you. Carl Jung, the great psychologist, said that "We should not pretend to understand the world only by intellect; we apprehend it just as much by feeling." I am going to ask you to use your experience and intellect, but also I am going to ask you to express your feelings about this challenge. I want you to bring not only your love and concern but, if necessary, even your anger to this issue. I am asking you to get involved. Adding

feeling to intellect will bring the best in each one of us out and will bring us the best of what this Conference can give to the smallest of America's citizens.

I am asking you, as a parent, official, teacher, or health care provider, to bring your honest perceptions of what can help families and children to be healthy and ready to learn. If we do not face the barriers or address the concerns, then we become a part of the problem and not a part of the solution. We know we have problems, but we also have great resources and strengths, not the least of which is America's devotion to its children. We need a commitment from each person here today and the organizations they represent so that they will bring their best knowledge and most profound human commitment to this issue. Perhaps our greatest challenge is to join hands and recover a true American spirit. This is the most caring country in the world, and today we will bring this concern to the lives of our children.

HEALTHY CHILDREN - Ready to Learn -

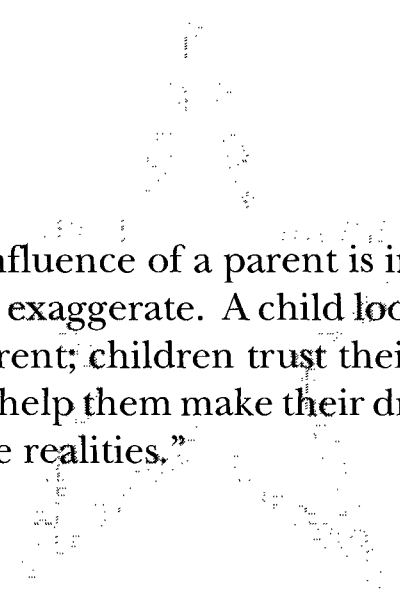


We are focusing on the role of parents—all of us, whether the President, Cabinet officers, Federal officials, Governors, or State officials. Some of us might be parents; others may not. But today, for the duration of this Conference, let's take the honorable position that each adult is each child's parent. Each American child belongs to each of us. No one parent or program can help each and every child, but together we can strive for the common goal of making each child as healthy and ready to learn as possible.

I would also remind you not to get discouraged about the Federal Government. This is your Government, and it is a powerful one. We are going to teach you what a powerful tool it can be. We are going to teach you how to use it. We have created, improved, and extended Head Start. We have changed immunization policies to protect children against a deadly revival of measles and other childhood illnesses. We have gotten involved in improved nutrition programs. We want you to know that we are here to work with you.

Let me expand just a moment on measles. We have had a very successful Federal/State/private campaign to increase immunizations. Granted that measles often appears in waves and that we have been in a bad wave, but let me point out that the rate of measles has dropped 65 percent between 1990 and 1991, from 27,786 cases in 1990 to 9,488 cases in 1991. We had only about 1,500 cases of measles in 1983, so you can see we still have far to go to reduce measles completely. The public and the private sectors have mobilized; everyone has responded. Dr. Sullivan, Dr. Roper, Dr. Mason, and I are finishing a six-city tour and have visited clinics in San Diego, Detroit, Philadelphia, Rapid City, Phoenix, and Dallas to encourage immunization.

This past Friday, we visited an immunization clinic in San Diego with President Bush. Hollywood celebrities took on measles immunization as their cause and formed the Children's Action Network. The Public Health Service has responded admirably, but there is still more to be done. Let me make this point. When we join together—parents, communities, and the government—when together we think and care, we can turn any epidemic around. We have both the means and the will.



“The influence of a parent is impossible to exaggerate. A child looks up to a parent; children trust their parents to help them make their dreams become realities.”

More than 2,000 years ago, Plato said, “The direction in which education starts a man will determine his future life.” I believe that. I know it to be true in my own life. My mother has been an educator all her life, and she believes that education is the greatest gift of all. She was the one who encouraged me to use education as a tool for success. All of us learn the dimensions of a larger world from our parents. The influence of a parent is impossible to exaggerate. A child looks up to a parent; children trust their parents to help them make their dreams become realities.

It was a long way for me from Fajardo, Puerto Rico, to the Office of the Surgeon General, but it was not an impossible way. Education made it possible. I would ask you to remember, too, that exceptional teacher who touched and inspired you as a student. Think what a teacher can do. As parents, educators, and health professionals, we must remember the influence we can have on the future of our children.

When President Bush outlined his six National Education Goals for the year 2000, he envisioned an America where our children compete on an international level. He knew that the children of today are the explorers, writers, teachers, and inventors of tomorrow. We must teach them all that we know and provide them with those tools they need to make their dreams come

true. Our children are very smart; some of them are smarter than any of us ever were. They are eager to learn, and we must not fail them.

We have some hard facts to face. Our educational system is unsurpassed at helping children excel at all levels, from diverse backgrounds, and often with English as a second language. Our public schools and our concept of an educated society are the source of America's strength and its potential. Still, we must face the truth. Scholastic Aptitude Tests (SAT) scores continue to remain low. We are not doing well in math and science. Many of our schools are overcrowded and overburdened, and many of our teachers are set up to fail by having too many children to teach.

"We can't become discouraged. Our teachers, children, and future depend on our dedication to turn things around. Some will tell us that it can't be done or that it just might be beyond hope. But I know in my heart that isn't true."

We can't become discouraged. Our teachers, children, and future depend on our dedication to turn things around. Some will tell us that it can't be done or that it just might be beyond hope. But I know in my heart that isn't true. The President and the Nation's Governors are working to remedy these problems—to make our schools the institutions for learning that they were meant to be and are capable of being. Collectively we must work to make that a reality.

As Surgeon General, I am responsible for the health of the people of this great country. That means all cultures, races, mothers, and fathers. And to me, as a pediatrician, it especially means children. When I was appointed Surgeon General, I resolved that my agenda would focus on the needs of our Nation's children. It is an overwhelming task, but it is an altogether necessary one.

When the President announced his six National Education Goals, there was, and continues to be, great enthusiasm for the promise of these goals. The first National Education Goal, that "By the year 2000, all children in America will start school ready to learn," holds special importance to me. This goal is realistic, and it is achievable. I believe those of us here in this room can be instrumental in implementing it in our own schools and communities. I know it is worth our best efforts.

As part of this first National Education Goal, we must work to satisfy three objectives:

- ★ First, that all disadvantaged and disabled children will have access to high-quality and developmentally appropriate preschool programs that help children prepare for school.
- ★ Second, that every parent in this country will be their child's first teacher and devote time each day helping his or her preschool child learn; that parents will have access to the training and support they need.
- ★ And last, that children will receive the nutrition and health care needed to arrive at school with healthy minds and bodies, and the number of low-birthweight babies will be significantly reduced through enhanced prenatal health systems.

These three objectives are the keys to our children arriving at school healthy and ready to learn, and your participation is crucial.

This Conference has been structured to give each one of you the opportunity to participate and to listen to what the esteemed panelists, Government representatives, and keynote speakers have to say. Most importantly, this Conference has been structured to give you

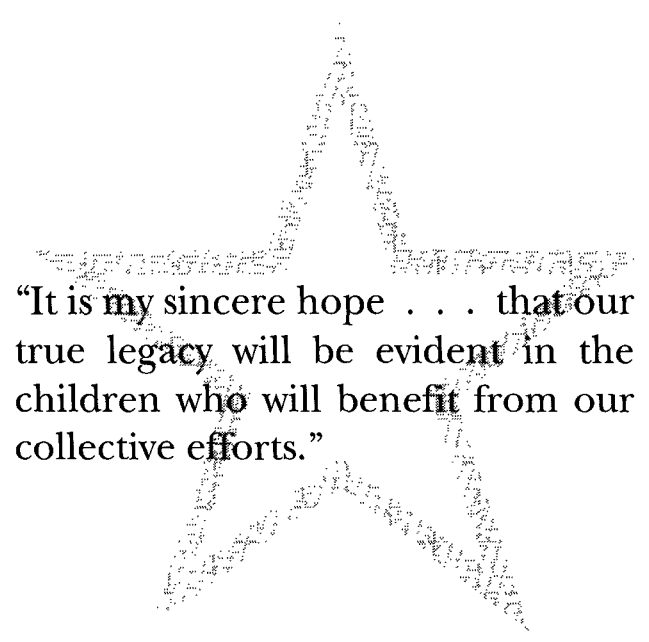
the opportunity to participate in these discussions and in the dialog that follows.

Those of you here representing the 50 States and the Territories will be able to tell the rest of us what works and what doesn't work in your States and communities. There is always room for improvement, growth, and change. We are going to talk about the good and the bad. By doing so, we will be able to avoid mistakes along the way and help, in turn, to highlight and applaud the success stories and use them as models as we move toward the year 2000.

Today, there are 64 million children in this country. We have 19 million American children under 5 years old and 4 million under 1 year. More than 20,000 children a year are killed by injuries. Some 1,677 have died from AIDS since its outbreak. Childhood diseases, due to a lack of vaccines, have disabled or killed thousands more. Although I am very hopeful, we must be honest. The statistics are staggering.

What can we, as a Nation, do? What can I, as Surgeon General, do? For one thing, I am always going to keep you informed, and I am going to tell you what you can do to help the Department [of Health and Human Services] and the Nation. To start, the goal of the Department of Health and Human Services is to have 95 percent of children immunized by 1995 and, hopefully, all of our children immunized by the year 2000. If you are a parent, see that your children are immunized, and tell other parents, too. If you are an official, check out the situation in your own area and help make immunization for all children a reality. I believe that immunization is a right, and we must all get involved to make that right a reality. To be successful, all vaccines must be used if they are going to work; they do us no good by sitting in a clinic or a doctor's office somewhere. I must make one point perfectly clear: We do not suffer from lack of vaccine; we suffer from failure to immunize. The immunizations are available; we need to get them to all of our children.

With regard to the terrible pandemic of AIDS, it is here that we must increase our vigilance to stop its spread. We must educate about AIDS, help everyone involved in the care of those with HIV disease, and send



"It is my sincere hope . . . that our true legacy will be evident in the children who will benefit from our collective efforts."

the message that we must fight the disease, not the people with the disease. The number of pediatric AIDS cases continues to increase. Before 1985, 58 percent of the children reported with AIDS were from New York City, Newark, or Miami. After 1985, however, only 36 percent of children with AIDS were from these cities. AIDS in women and children is spreading beyond the large cities to smaller towns and even rural settings. The greatest increases in numbers of cases reported to the CDC [Centers for Disease Control] were in rural areas and in metropolitan areas with populations of under 100,000. From 1988 to 1989, there was a 12 percent increase in the number of pediatric AIDS cases. From 1989 to 1990, there was a 37 percent increase. As of August 1991, 3,199 children under 13 with AIDS were reported to the CDC, more than half of them in the last 2 years alone. Of these cases, 84 percent were infected perinatally, and 52.4 percent, or 1,677, have died. Based on the National Survey of Childbearing Women, the CDC estimates that 5,000 to 6,000 HIV-infected women gave birth in the past year. Based on a 30 percent transmission rate, it is estimated that 1,800 to 2,000 HIV-infected infants were born.

Children of minority families have had more than their share of AIDS. For example, although only 15 percent of all children in the United States are

African-American, they are known to account for 51 percent of all AIDS cases. Although only 8 percent of all children in the United States are of Hispanic descent, they account for 26 percent of AIDS cases in children. Clearly, all of us here must be prepared to deal with children and families with AIDS. But to do that, we must have culturally sensitive programs. We must know Harlem to design a program for Harlem, and we must know the barrios of Texas to be able to work there. Some programs must be in Spanish or in any language that is necessary. Parts of Appalachia can be as desolate as any inner city slum. We should not design programs for our communities unless we have walked in their shoes and in their streets. We must be humble and consult those who know those communities when we design any interventions.

The third point on which we all must continue to focus is that of childhood injuries. According to a recent health report issued by the Bureau of Maternal and Child Health, injuries are the most significant health problem affecting our Nation's children and adolescents, however we measure it—whether by numbers of deaths, dollar costs for treatment, or relative rankings with other health problems. Injury need not maim and kill so many of our children. The tide of injuries is an epidemic we can control. Childhood injury is one of the principal public health problems in America today, causing more deaths than all childhood diseases combined and contributing greatly to childhood disability.

The United States is also a Nation plagued by violence. American children are 10 times more likely than German children, 11 times more likely than French children, and 15 times more likely than English children to be victims of homicide. We could debate whether it is poverty or race that so intensifies patterns of morbidity and mortality, that so darkens the picture for violence, but now, suffice it to say that this has to stop. As Abraham Lincoln said in 1860, "Let us have faith that right makes might." Knowing we are right, let's dare to do our duty as we understand it.

I may as well admit that I see the Office of the Surgeon General as a way of reaching families, a way of reaching children. I have probably held more babies



than any Surgeon General in history. My schedule—ask my staff if you don't believe me—goes off the rails when I visit a pediatric clinic, an Indian Health Service hospital, a pediatric AIDS unit. I have talked in more high schools and in more small towns than I can remember. The Black Foot Indian Nation gave me the name "Princess Flying Woman." I believe they knew that I wanted to touch all Americans. For the time that is mine to serve as Surgeon General, I am absolutely committed to make a difference. I am making these confessions to warn you. I did not accept the responsibility for this Healthy Children Ready to Learn Initiative for reasons of status. I am as serious as you are.

I see our task as improving the health and welfare of our Nation's children in every way we can. By attending this Conference, you have made an excellent commitment on behalf of other parents and children

from your State, and for that I commend you. I urge you to participate fully in the panel sessions and discussion groups. We are here to teach and to learn from one another. We are going to, as the kids say, “get real.”

I know that any of you here would jump from your seat and take off in a dead run to grab a child from the path of a car. You would shield a child about to be hurt. You would endanger yourself to protect a child from a dangerous fall. When it comes to health and education, we need a dead run; we need total intuitive conviction to remove every barrier and to reach every child. This Conference is geared to be that “dead run.”

When I was appointed I vowed to speak for all of the children. I vowed to be the Surgeon General for all Americans, especially for all American children, whether rich or poor, African-American, white, Hispanic, Asian Pacific Islander, or Native American—whether documented or not, from the President’s grandchild to the child of a Migrant worker. All our children need this attention, but there are some who especially need my voice. One in five American children lives in poverty; I speak for them. Thirty-eight percent of Hispanic children live below the poverty line; 43 percent of all African-American children live in poverty. I speak for them, too.

In the words of the Chilean poet, Gabriela Mistral:

*Many of the things we need can wait;
The child cannot.
Right now is the time his bones are being formed, his
blood is being made,
and his senses are being developed.
To him we cannot answer ‘Tomorrow’;
His name is ‘Today.’*

Today, as parents, you are both the expert and the student, and I ask all experts today to think also as parents. By all means, play both roles. By the year 2000, chances are that any one of us may be only a distant memory. It is my sincere hope, however, that our true legacy will be evident in the children who will benefit from our collective efforts. They will be children who started school healthy and ready to learn, children who learned and learned well, children whose parents taught

them first and set the stage for the teachers who followed, children who were immunized and well nourished, children who have had all that America can give.

The time has come for me to turn the focus back on you and ask all of you within this room to work together. We have a precious opportunity to spend 3 days at this Conference to think, argue, forge new initiatives, prioritize, and get involved. It is my fervent hope that the goals of this Conference will become a blueprint for bonding education and health—an essential task, if our children are to succeed.

I wish you the best in your endeavor. God bless you all.

Chapter 3

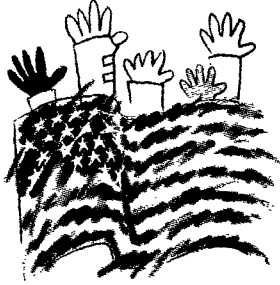
Parents Speak Out: Summary of Parent Work Groups



Chapter 3

Parents Speak Out

HEALTHY CHILDREN

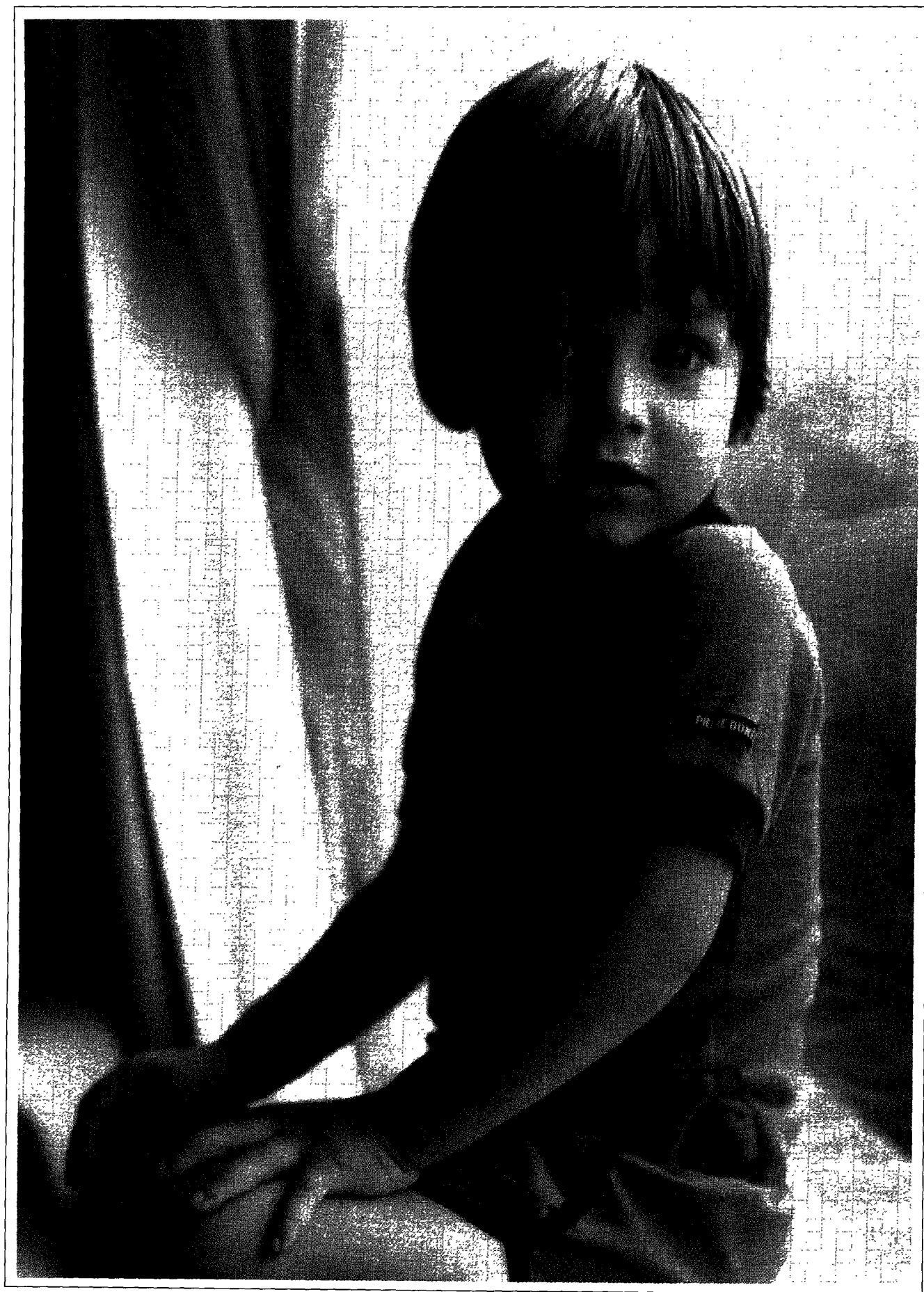


--- Ready to Learn ---

SUMMARY OF PARENT WORK GROUPS

During the Conference, the State Parent Delegates attended work groups to which they were assigned according to the geographical regions in which they live. Native American and Migrant parents could choose to attend the regional work groups or separate work groups, which were established to ensure that their special needs or issues were not lost. In all the work groups, roundtable discussions were held to discuss three topics representing stages of families' involvement with health, education, and social service systems: awareness of and entry into the systems, participation in the systems, and transitions from one program to another as families move through the systems. In their discussions, the parents examined three main questions related to these stages: (1) What is my role as a parent in this stage of working through and with the systems? (2) What are the barriers or other issues I face in this stage? (3) What are some solutions to these problems, and what are some existing model programs that incorporate some of these recommended solutions?

This section details the issues raised by the parents. First, a summary of the national consensus, broken down by topic, is given. The national consensus summary contains issues raised by several of the work groups and upon which they were in agreement. Next are summaries of the comments made by each work group (regional, Native American, and Migrant). To avoid repetition, these descriptions may not include issues contained in the national consensus. Their purpose is to highlight the issues that were of particular concern to the specific work group rather than to provide an exhaustive list of issues discussed in each work group.



National Consensus

Findings at a Glance

Awareness of and Entry into Health, Education, and Social Service Systems

Roles and Responsibilities of Parents

- ★ Identify their children's needs
- ★ Interact and communicate with their children on a daily basis
- ★ Consider themselves equal partners with professionals who also care for their children
- ★ Participate in networks and support groups

Barriers and Issues of Concern

- ★ Confusion about the systems due to limited available information or contradictory information
- ★ Too much "red tape"
- ★ Cultural insensitivity and communication barriers
- ★ Poor attitudes and intimidating behavior of service providers
- ★ Poor pay and lack of incentives for providers to accept Medicaid
- ★ Inflexible hours of programs, clinics, etc.
- ★ Transportation problems/inconvenient locations of service facilities
- ★ Inflexible criteria for eligibility to receive services
- ★ Lack of accountability within the systems
- ★ Inadequate funding of needed services

Solutions

- ★ Universal application form to apply for an array of services, such as WIC, Head Start, Food Stamps, etc.
- ★ One-stop shopping, with assigned resource coordinator for each family and provision of service directories, including toll-free hotlines
- ★ Flexibility in criteria to establish eligibility to receive services
- ★ Convenient operating hours for programs and facilities
- ★ Elementary school curricula in social competency and parenting skills
- ★ Funding for support groups for families
- ★ Mechanisms within the systems for establishing accountability and for halting complaints
- ★ Rotation of service-provider staff to prevent employee burnout
- ★ An awareness campaign to promote the importance of healthy children
- ★ Development of a national health care policy

Participation in Health, Education, and Social Service Systems

Roles and Responsibilities of Parents

- ★ Become empowered and become role models for their children and other parents
- ★ Serve as advocates for their children, for other parents in the systems, and for the programs that provide services to them
- ★ Be involved in program activities and work with service providers in meeting their children's needs

- ★ Train service providers in their culture and unique family characteristics
- ★ Be involved in program decisionmaking and in evaluating services

Barriers and Issues of Concern

- ★ Bureaucracy, inflexible hours, and transportation problems
- ★ Gaps in services
- ★ Lack of coordination among services
- ★ Lack of a family-centered philosophy
- ★ Insensitivity not only of service providers but of the public at large
- ★ Lack of incentives for families to become independent
- ★ Rigid eligibility requirements
- ★ Inequities in funding for education
- ★ Frustration with the systems
- ★ Hesitation in confronting the systems
- ★ Need for support groups

Solutions

- ★ Training in parenting skills, beginning as early as elementary school
- ★ Improved communications among service agencies and central community resource clearinghouses (one-stop shopping)
- ★ Paid positions for parents on boards that oversee programs
- ★ Employment policies that support families, such as family leave
- ★ Secure and increased funding for programs
- ★ Media campaign to improve public opinion of families receiving services
- ★ Election of government officials who support families
- ★ Expansion or adaptation of model programs to reach more communities and families

Transitions *Through Health, Education, and Social Service Systems*

Roles and Responsibilities of Parents

- ★ Be active participants in the transition process
- ★ Be good recordkeepers
- ★ Demand respect and develop self-esteem for themselves and their children
- ★ Be a good role model for their children and for other parents
- ★ Define the role of parents for professionals in the systems

Barriers Families Face During Transitions

- ★ Lack of communication among programs and the need for one-stop shopping
- ★ Failure to receive copies of children's records; records that contain technical jargon or that are not translated into parent's native language
- ★ Lack of sensitivity
- ★ Lack of consistency in parental involvement across programs
- ★ Need for support groups
- ★ Too much paperwork
- ★ Transportation problems
- ★ Inflexible programs and facilities
- ★ Lack of employment policies that support families
- ★ Abolishment of programs because of unstable funding

Solutions

- ★ Toll-free hotlines and resource directories
- ★ Sensitivity training for service-provider staff
- ★ Mentoring of new parents in the programs by system veterans
- ★ Guidance for parents provided by doctors, hospitals, and other service providers
- ★ One-stop shopping and assignment of one case-worker per family for all programs
- ★ Reform of eligibility requirements to consider net pay, examine hardship conditions, and provide a safety net
- ★ Legislative action, such as family leave policies
- ★ Assertiveness training for children by their parent

Awareness of and Entry into Health, Education, and Social Service Systems

The parents willingly accept their responsibility as the primary provider of their children's needs. However, they also acknowledged that every family needs help occasionally. Federal, State, and local programs can support informed parents who enroll their children into these programs. Unfortunately, lack of information, bureaucracy, and inflexibility in service provision prevent many families from benefitting from these programs. The parents maintained that programs must be coordinated under the one-stop-shopping approach to supply flexible and accountable service.

Roles and Responsibilities of Parents

The delegates recognized that they must first identify their children's needs. Children need to be immunized, given a proper diet, nurtured, taught self-respect and respect of others, taught learning skills, provided

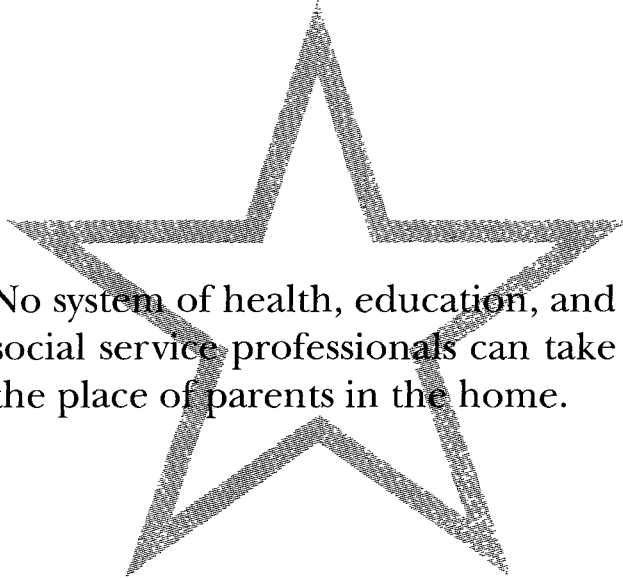
AWARENESS

with a safe, stable home environment—the list is long, covering the full range of physical, emotional, and spiritual development. No system of health, education, and social service professionals can take the place of parents in the home. Parents must take the time and effort to know their children. Federal, State, and local programs can serve only a supporting role as parents struggle to raise healthy children.

Daily interaction and communication with children is key. Good parents listen to their children, not only when they complain or are sick but also at other times. Parents with special needs children must make an additional effort to maintain balance within the family and to devote attention to healthy siblings. All children, however, can benefit from existing Federal, State, and local programs, and parents must take the second step of finding out what the programs are and what they have to offer toward meeting their children's needs. There is no substitute for the well-informed parent.

The delegates maintained that parents should consider themselves partners on equal footing with

professionals and other care providers and be recognized as such. Parents who know their children's health needs and risks and the services available to support them make self-confident parents who can work effectively with care providers. While respecting the judgments of professionals, parents should not surrender the decisionmaking to them; when professionals give advice that seems questionable, parents should trust their own instincts enough to seek second opinions. As advocates for their children, parents should be assertive and persistent but should not forget to be diplomatic. The way they interact with care providers will influence how their own children behave toward others. Good partnerships are respectful partnerships.



No system of health, education, and social service professionals can take the place of parents in the home.

Finally, the delegates agreed that networks and support groups are a tremendous asset. Parent networks can provide information, moral support, and hands-on care, and can make up for some—though certainly not all—of the failures of the present health care systems. Networks can help parents at all stages of their children's health care, but most of all in the entry stage, as they make their first tentative and sometimes confused steps into the programs. When an individual family questions a professional opinion, networks can supply alternative sources of information; when the family doesn't know where to turn

or what step to take next, networks can point the way. Networks allow parents to draw from the shared experiences of other parents and work together toward common goals. Not all parents entering the programs know their rights, and networks give them the opportunity to learn and exercise their rights in an unthreatening environment. Networks are effective in this way because they teach by example.

Networks can also help parents learn their responsibilities. Not all parents are responsible parents. While it is important that parents raise their children as they see fit, some fail to recognize that their children have special needs. The children may be physically healthy but have learning disabilities or behavioral or emotional disorders, and their needs may pass unnoticed. The parents may have alcohol and other drug problems or problems that lead to child neglect or abuse. These parents may deny that problems exist. They may be reluctant to seek help because they believe it is shameful to do so. Professional health care providers can intervene in such cases. However, professionals are often perceived as threatening and, as a rule, are less effective than parent networks in these especially difficult cases. Troubled parents are more likely to listen to other parents and to perceive them as partners rather than as authority figures. The other parents can, in turn, seek guidance from the rest of the network as it shepherds the family into the health care systems.

Barriers and Issues of Concern

The most often cited problem of parents being aware of and entering programs was confusion about the systems. To many parents, the systems seem designed to discourage them from the start: To withhold information and frighten them away with paperwork. No single source of information on the many available resources exists, and information provided is often contradictory. In addition, many employees of the programs don't even know how the systems work, nor do they know how to access the information that can help parents find their way.

The amount of red tape is enormous; application forms are long and complicated. To make matters

worse, different agencies have different application forms, and parents are forced to repeat the same complicated procedures as they try to move from one agency to another. As one parent stated, "The paperwork doesn't flow."

In addition, application forms make no allowances for the diversity of applicants. Parents who are not native English speakers often have great difficulty trying to make sense of the forms. Even fully fluent English speakers make this same complaint. No allowances are made for cultural differences or for the communication styles of minorities. Alternative services for the blind and the hearing impaired are also lacking.

Many delegates complained that the attitudes and behavior of social service workers and health care providers can be patronizing, unfriendly, intimidating, and sometimes even abusive. They believed that a great many social service workers suffer from employee burn-out. Workers are not sensitized or properly trained, and they therefore bring their prejudices to the workplace. Parents entering the programs feel this most strongly, while those at later stages come to expect a certain degree of mistreatment as part of the price they must pay in exchange for services. "It's hard to get into the system, and once you get in, you don't want to stay," stated one delegate. But their needs force the parents to stay, with the result that they come to feel as trapped by the systems as by the needs that brought them to seek help in the first place.

As for health care providers, their attitudes and behavior tend to reflect their own unhappiness about how poorly they are paid for the services they provide. Medicaid, for example, pays providers so little that they have no incentive to take Medicaid patients. As a result, the patients often receive inferior care or are refused care outright. Ultimately, the patients are the ones who suffer from inadequately funded programs that fail to deliver on their promises. The health care centers themselves often present a variety of physical barriers to disabled children.

Another concern was the lack of flexibility in office hours. Social service and health care providers



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who hold 9-to-5 office hours are making no allowances for working parents. The working parent who has to leave work—losing a morning, an afternoon, sometimes a whole day in the process—to meet these inflexible hours may be at risk of losing his or her job. This situation, in turn, may put the child at risk of forgoing important preventive medical services such as immunizations and well-child checkups.

Transportation is a related problem. Parents often have to take long hours away from their jobs because they have to travel long distances to their appointments, and they often have to rely on either public transportation or help from friends. This problem is particularly acute in remote, rural areas.

The delegates expressed unanimous dissatisfaction with eligibility criteria. The criteria are artificial and inflexible. They do not reflect real income—net income, after taxes—and applicants can be denied entry into programs if their income exceeds the criteria by as little as a few dollars. A family may meet the criteria one year, only to be disqualified the next because of a slight rise in

income. While the eligibility criteria are meant to prevent abuses, the criteria themselves often foster dependency. In many cases, a family can benefit in the short run—qualify for Food Stamps, for example—if one of the parents quits a job so as not to exceed the eligibility criteria. Quitting a job can actually mean more food on the table. Under some welfare programs, a family can qualify only if the father leaves home. “You learn to play the game,” one parent said. Parents take these steps, not because they are lazy or cynical but because they have immediate needs and feel they have no other choice. However, the choices they make often mean that dependence on welfare programs is handed down from generation to generation.

Parents who try to make this point with social service workers feel even more frustrated. They face a bureaucracy from the moment they enter a program, and they either adapt to the bureaucracy or go without services. If they feel they are mistreated, they have no one to turn to within the systems. They see a general lack of accountability and are often afraid that if they

protest, they will be denied services or subjected to further mistreatment.

Inadequate funds are an underlying problem for all programs. Because there are simply not enough dollars to go around, programs serving the same communities are forced to compete for the same dollars. This competition creates divisions within communities, and the rifts are often felt in the parents' networks. Parents will naturally fight for the children, but when they are forced to fight other parents, the real losers are the children.

Solutions to Promote Awareness of and Entry into Systems

First among the proposed solutions was a universal or near-universal application form for all services, with consistent eligibility criteria. The form should be easy to read. Alternate versions of the same form should be made available to parents who are not native English speakers. Special arrangements should be made for the blind, the hearing impaired, and applicants with low literacy levels.

There should be a single point of entry for all services, i.e., one-stop shopping. When families enter the bureaucratic maze, they should be able to consult a single source for comprehensive information on available services and referrals. A resource coordinator should be assigned to each family, and the family should be provided with local, State, and national directories of available services. Toll-free hotlines for resource information would be a useful supplement.

Eligibility criteria need to be more flexible. The criteria should be based on real (net) income. Inflexible criteria often foster dependence on the systems, as parents quit jobs or avoid seeking employment and fathers leave households so that families can meet eligibility criteria. Greater flexibility will promote self-help.

Agencies must also have flexible working hours—not just 9 to 5—in support of working parents. Many parents risk losing their jobs if they have to take time off from work to meet appointments with care providers.

Programs should be instituted in elementary schools to develop social competency and parenting skills and to

help train children to be effective parents and advocates for their own children someday. The characteristics taught should include self-esteem, problem-solving and decisionmaking skills, and respect for others.

Funds should be made available to help create and maintain support groups. Support groups are popular: they encourage parents to take a more active role in raising their children; they develop parenting skills; and, because they promote self-help, they can actually lighten the burden of social service systems. As one parent stated, "The best program is the program that doesn't cost anything," in other words, that encourages independence. Support groups are the closest known approximation to that ideal program. They can be developed at the neighborhood level, at the workplace, at schools, or within the tribe, and they can be tailored to any number of specific needs.

Parents need a way to talk back to the systems. Parents are partners with service providers, and the true beneficiaries are the children; when the partnership breaks down, the children pay the price. Parents should be treated compassionately and with respect. A mechanism should exist by which parents can submit evaluations of the services they receive and register complaints when necessary. Complaints should be addressed in a timely manner. The bureaucracy must be more accountable, and accountability must be on site to be effective. Parents who have been recipients of programs should serve on agency advisory boards.

Many delegates expressed the belief that employee burnout is responsible for much of the rude treatment parents receive. The delegates suggested that rotating employees to different posts within agencies could help prevent burnout and would certainly result in better informed employees who can then pass their knowledge on to needy families.

An all-out effort needs to be made to raise public awareness as to the importance of healthy children. Antismoking and AIDS awareness campaigns have proven effective; children should be the next focus.

Together with a media campaign on children as an investment in the future, this country should initiate an energetic debate on our national health care policy.

Is health care a right or a privilege? Is health insurance a right or a privilege? We cannot expect to move forward on particular solutions without defining our values and goals in specific, practical terms.

Participation in Health, Education, and Social Service Systems

As families participate in health, education, and social service systems, parents must seek education for themselves and become empowered, the delegates maintained, so that they can become role models for their children and for other parents whose families need services. Furthermore, programs should offer incentives for parents to become empowered and for their families to become independent. Programs need to become family centered, and parents need to be involved in program decisionmaking to keep programs focused on providing quality service to meet families' needs.

Roles and Responsibilities of Parents

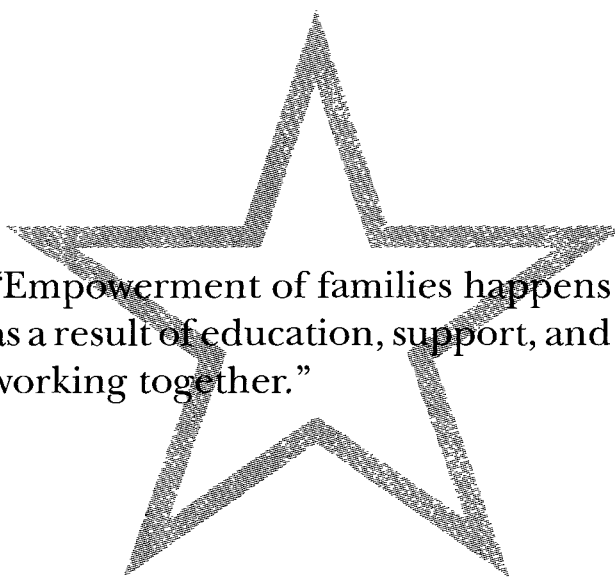
The delegates agreed unanimously that the parents'

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primary role of nurturing their children does not change as their families participate in health, education, and social service systems. Parents of children who receive services do not relinquish their role as the primary advocates for their children and as the parties responsible for ensuring that their children's needs are met. On the contrary, the delegates expressed that participation in programs brings added responsibilities to the parents. The delegates contended that parents in families receiving services have an even greater responsibility to become empowered themselves so that they can empower their families. They stressed that parents must seek education, when necessary, and good mental health; they stated emphatically that parents have the responsibility to be "emotionally and socially straight." As parents become empowered, they become role models, not only for their children but for other parents in the community.

An important function of parents whose children receive services in serving as role models is to reach out to other families and enlist them into the programs. When new families are enlisted, declared the delegates, these parents have a responsibility to help orient the new families in the programs by providing them with information and offering their support. In this way, parents serve a dual advocacy role—for new parents, by offering their support, and for the programs, by publicizing their services and being committed to them. This commitment may involve lobbying for endangered programs. As parents serve as advocates and network with other parents, they can build community support for families. As one delegate stated, "Empowerment of families happens as a result of education, support, and working together."

Working together, the parents insisted, also means working with the service providers. Parents can support the efforts of professionals working with their children by being involved with the programs' activities and offering supplemental exercises at home. Parents should ask teachers or other care givers for activities that they can use at home. Working together for the children's benefit can build trust among professionals and parents, with the result that service providers may begin to view parents in the manner that they so fervently desire, i.e., as experts where their children



"Empowerment of families happens as a result of education, support, and working together."

are concerned and as respected partners in providing for their health and education.

Parents also have a responsibility to train service providers in the culture and unique characteristics of the families they serve. Only the parents can educate the community about the special problems of minority families, for instance. Programs must understand the communities they serve to adequately meet their needs.

Repeatedly, the delegates insisted that, as respected partners, they should have a voice in the programs that serve their families. They contended that, because they have a vested interest in the quality of service, they should be involved in all aspects of the programs, from program design to budgets and hiring decisions. The parents' role should extend from planning and implementing programs to evaluating them and their services. After all, the quality of services affects the parents directly; they are the first to know when needs are not being met.

Barriers to Participation and Issues of Concern

On the topic of participation in health, education, and social service systems, parents reiterated many of the complaints that they had expressed concerning awareness of and entry into the systems. The frustration with the systems does not end when families become involved, they stated, citing the same difficulties in obtaining information, inflexibility in hours and services, transportation problems, and language barriers. Nor does the amount of "red tape" decrease once a family is participating in the programs. Stated one delegate, "Bureaucracy often discourages participation."

The delegates were also concerned about gaps in services, which service providers often do not address directly but instead "pass the buck," sending the family from one provider to another in search of the needed service. The supply of services is often inadequate to meet the demand, resulting in long waiting lists or the use of quotas. For instance, the lack of affordable daycare was a problem cited by many delegates.

The delegates attributed many of these problems to two principal factors: lack of coordination among programs and the absence of a family-centered philosophy.

Coordination and collaboration among programs would facilitate the identification of gaps in services, as well as duplication, so that resources could be used more efficiently to meet the needs of clients. The implementation of a family-centered philosophy would ensure that programs would provide parents with the necessary information, would have flexible hours, would be conveniently located, and would consider their families' cultural and language backgrounds, not only in their printed materials but also in their policies and procedures. The delegates also stated that leadership is lacking at the Federal and State levels, resulting in a resistance to such changes in the systems.

The insensitive attitudes of service providers often extend to the public, the delegates maintained, leading to a "national psychology" that looks down on parents receiving services. Delegates shared the embarrassment of themselves and friends created by comments that other customers in checkout lines make regarding their use of Food Stamps. The delegates want the general public to know that parents whose families receive services care about their children and that their misfortunes can happen to anyone. "Our country is not segmented into welfare recipients and the rest of us," one parent insisted. In fact, most people in this country benefit from some kind of public funding, for example, farm subsidies.

As we improve our attitude toward families receiving services, the parents countered, we must not let them become apathetic or complacent, with the result that they are dependent on the systems. The delegates repeatedly said that the systems need to offer incentives to parents to become independent. Often, they said, programs provide a quick fix for crisis situations without addressing the underlying causes. True healing cannot begin, they said, until the systems provide a holistic approach to treating family problems. As one parent said, "There is a sense of futility on the part of some families, a lost sense of what they could be reaching for and what they might achieve."

Some delegates complained that middle-class children often are "squeezed out" or "fall through the cracks" between programs because the families are not

eligible for services; yet the parents cannot afford to provide for more than the child's basic needs. Health care, for instance, was a major concern; the delegates reiterated that every family has a right to adequate health care. Once again, the parents criticized the rigid eligibility requirements.

This situation also extends to education, they maintained. They contended that inequities in funding in the local school districts automatically precludes "equal education for all," and middle-class children often are not eligible for special educational programs. They urged that these funding inequities should be addressed.

Finally, the parents expressed again their frustration in confronting the systems to achieve positive changes. Even parents who are actively participating in systems hesitate to make waves. Said one parent, "If you act assertively, you are isolated." They reiterated the need for family support groups and funding to organize them.

All of these problems can be overwhelming for

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parents at times. One delegate summed up this sentiment with the following remark: "The children are our future, and it's scary."

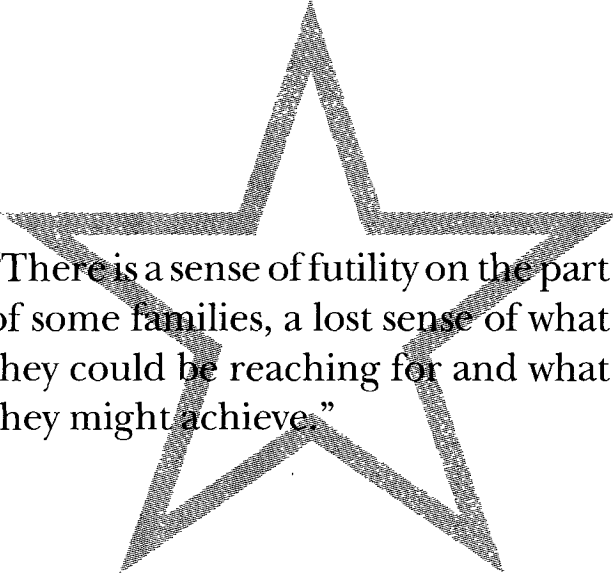
Solutions to Facilitate Participation

Although the problems may seem overwhelming, they are not insurmountable, the parents stated emphatically. They recommended taking steps in the following areas to begin to break down the barriers to producing healthy children ready to learn.

First, the parents advocated that training in parenting skills should begin early, before a youngster becomes a parent herself or himself. They pointed out that our young people receive limited training, at best, for their most important role. Most of us follow the parenting styles of our own parents, but not everyone is fortunate enough to have loving and nurturing parents. Early training in parenting skills is imperative.

The parents stressed that, for parents who need services, improved communications among service agen-

cies would solve many problems. Improved communications would facilitate entry into and participation in programs because service providers would be able to guide families to the most appropriate program to meet their needs. The delegates recommended central community resource clearinghouses. Such clearinghouses should be staffed with culturally sensitive employees, should provide the paperwork to apply for services (preferably through the use of the universal application form), and offer flexible hours. Such a facility would lead to better coordinated services and a reduction of gaps and duplication in services. It would



"There is a sense of futility on the part of some families, a lost sense of what they could be reaching for and what they might achieve."

be a first step toward implementing a one-stop shopping approach. In addition, the delegates recommended that resource hotlines be established, that directories of services be published, and that each community's telephone directory include a directory of local services and resources.

To move toward a family-centered philosophy in the systems, the delegates recommended that parents be elected or appointed to the boards that oversee programs. Through their positions on the boards, the parents could offer input, not only in planning but also in evaluating the programs that serve them. Parent input would keep the programs focused on the bottom line: providing quality service to meet the needs of

families. The delegates added that parents should be compensated for their work and the expertise they would bring to the planning and evaluation processes. Without compensation, they asserted, the parents would find it more difficult to gain the recognition they deserve as respected partners.

Employers also need to recognize the importance of families and develop policies accordingly. The delegates expressed a need for flex-time so that they can more easily attend to family matters. The work groups universally endorsed the passage of a family leave act. They also recommended that employers support daycare centers for their employees.

Secure and increased funding for programs to ensure their continued existence would also improve participation in the systems, the delegates maintained. Funding is particularly important for parent support groups. In addition, the delegates recommended that funding mechanisms for education be changed. Furthermore, they recommended overall reform of the educational system.

The delegates urged that a “national psychology” be developed acknowledging that all children and families have the right to certain basic supports for their health and well-being. This attitude can be achieved through the media. One group maintained that the Surgeon General’s Office “has the power” to change public opinion through an advertising and public relations campaign stressing this concept. Television spots could show a respectful approach to families applying for services.

Another aspect of changing the national attitude is to elect officials who actively support families. The delegates urged that Americans become involved politically. If we are to solve many of the problems facing our families, they said, we must have committed leaders.

Finally, the delegates asserted that we have model programs that show us what works. We should adapt local model programs to other communities and expand model programs for special needs children to fit all children. Elements of the most cited model program, Head Start, could be incorporated in the primary grades, for instance.

Transitions Through Health, Education, and Social Service Systems

All parents and children experience transitions. The Parent Work Groups agreed that parents, agency officials, and community people all have roles and responsibilities in the successful transition of children through health, education, and social service programs. Being ready to learn, they said, is more than making children ready for schools; it’s also making schools ready for children. They concluded with what they called the “rule of the three C’s,” which they said drives successful transitions: Consistency, continuity, and coordination of services are all necessary to promoting healthy children—and families—ready to learn.

Roles and Responsibilities of Parents During Transitions

As they discussed parental roles and responsibilities in transition, the 12 work groups centered their thoughts on the following question: How do we, as parents,

TRANSITIONS

ensure a smooth transition from birth through infancy to early childhood to being healthy and ready to learn for entering school? One response was sounded repeatedly: Parents need to be active participants in the transition process because they are the best evaluators of their children’s needs, including health and special equipment needs. To participate in transitions, parents must be prepared for the transition process. A transition from one program to another requires adjustments for both parent and child. Therefore, a smooth transition begins with the transition of the parent. Examples of ways the delegates have participated in transitions and prepared their children for them included touring a new school or health facility with the child, introducing children to new people to acquaint them with new teachers or specialists, and learning a program’s daily routine and talking to children about it before immersing them in it. The groups all agreed that making these preparations for any transition is important to everyone’s well-being. The parents recommended that health providers, school administrators,

and service providers develop transition resource manuals concerning their programs and services for families.

Agreement was unanimous that parents must be good recordkeepers in order to make successful transitions; the parents must also ensure that records are transferred when a child makes a transition out of one health, education, or social service program or system and into another. These records, the delegates pointed out, include financial records for program eligibility, medical records for immunizations and tests taken, and school records for credits.

During transitions, as well as in other stages of working with the systems, the delegates said parents must demand respect and develop self-esteem for themselves and their children. To help ensure children's self-esteem during transitions, parents must make sure the children know their feelings about transition are important. Some parents have a special responsibility for developing the self-esteem of their children and making transitions smooth. Parents with children in

TRANSITIONS

special programs, for example, must make sure they don't fall prey to the stigma that others often create when children need more than usual services. The parents complained that practitioners do not value parents as human beings. They were critical of people administering health, education, and social service programs who sometimes act as though they own the children. Phrases such as "parents are professionals, too" and "label cans, not kids" were voiced throughout the conference.

The delegates agreed that parents need to be good role models, and becoming good models sometimes means finding good models for themselves first. It also means that parents need to watch out for other children in the community, and teach better parenting skills to parents who don't adequately fulfill the role of parent.

As the conference was ending, one delegate commented, "I thought I was a pretty good parent when I came here. But with all I've heard and learned here, I know I'll be a better parent in the future." The other delegates agreed with this sentiment and added that the

Conference has given them a new role: They have been charged with the responsibility of returning to their communities to meet with officials of programs that affect their children and to define the role of parents for the professionals involved.

Barriers Families Face During Transitions

To open a dialog on barriers to successful transition, the delegates focused on one question: What makes it difficult for my child and me to move from one program to another?

One universal need for making transitions more successful was for parents, providers, and government officials to improve communications. The parents felt that better communication among agencies would decrease turf wars, prevent duplication of services, and promote the continuity of services. The delegates voiced concern that, too many times, they have found that professionals in office A don't know what programs are available through office B—even when A and B are under the same umbrella agency. The parents pointed out that one-stop shopping is just as important for smooth transitions as it is for entry into programs. They also called for development of one universal application form for a variety of public assistance programs, such as WIC, AFDC, and Food Stamps. They insisted that transitions would be smoother if files were tracked through a computer system that is accessible to staff in all State programs.

Parents said they need to receive the reports written about their children so that they can assume the role of recordkeeper. But if reports and other program materials are to be useful, they cannot contain technical jargon. Instead, they must be written in the language of the parents. That might mean having materials in foreign languages for parents who do not speak English or having them developed as picture books for parents who are illiterate. One delegate told of a Spanish-speaking mother of a mentally retarded girl who attended public school. For 4 years, the mother did not know about the child's educational progress, problems, or needs because everything she received from the



school was written in English, and none of the school staff spoke Spanish.

Parents repeated that, during transitions (as in other phases), program materials and staff must be sensitive to all different types of cultures; they must be sensitive to social and financial status, too. The delegates complained that case workers tend to stereotype and pigeon-hole people, too often ignoring clients' backgrounds and histories. Successful transitions, the delegates said, depend on everyone involved trusting each other; inappropriate communications do not breed trust.

Another universally noted need was for parents to be involved consistently during transition. Parent boards that are proportionately representative of ethnic, racial, and cultural differences give all parents an important voice in program design and policymaking, which can help them prepare their child for transition. After transition occurs, parents still need to be involved. The parents repeatedly cited Head Start as a good example of a program that keeps parents involved; but after Head Start, parents need to make an extra effort to stay involved in their children's other educational opportunities.

The delegates said that support groups are needed even more during transitions, and they advocated that programs work with support groups to make transitions more positive. But even if support groups are not available, delegates said programs should provide counselors to help get parents involved and to prepare them for transitions into and out of programs.

Once again, the work groups cited a need to decrease the time parents spend on paperwork by developing less complex forms. In addition, delegates said agencies must be directed to reduce the time they take to decide an applicant's eligibility. Implementing these changes would help families make more timely transitions and provide more motivation for families to move from one program to another.

Delegates from small towns everywhere pointed out that families in rural America often have no resources in their hometowns to meet some children's health, education, or social service needs; travel distances to available providers can be long, and public transportation is seldom available.

If transitions are to be successful, programs need to be as flexible as program administrators expect the families to be. Flexibility should begin with program eligibility criteria and then continue to the program structure and facilities. Many delegates remarked that family and individual needs still exist when income levels change, but eligibility criteria are often too rigid to accommodate the transition. Too often, the parents noted, agencies overlook the need for their offices to be open when parents can gain access to them, after traditional business hours or on weekends, for example. A story from one delegate, the mother of a child with physical disabilities, documents the need for flexible facilities. The child's classroom contains a restroom. However the delegate's son, who uses a wheelchair, and his attendant were not allowed to use these facilities because he requires more time than the other children. They had to go across the school gym to a communal restroom because the teachers didn't want the other children waiting in line for the boy. Some flexibility in the program would have made him feel more welcome and comfortable, and it would have made his transition to the classroom much more positive.

Labor laws need to be enacted to make employers more considerate of the needs of people with children, particularly poor working parents. One parent delegate surprised even her understanding colleagues when she told that her employer, a hospital, would not give her time off to come to the Surgeon General's Conference; she had to deduct the Conference from sick and vacation leave, which she also uses when her child has a medical appointment or a day off from school.

Parents reported that they and their children are constantly facing new transitions. They suggested that some of these transitions and their associated problems could be eliminated, if all levels of government would stop the frustrating practice of abolishing programs that families depend on without notice. Unstable funding from all levels of government is another frustrating barrier parents hurdle during transitions in health, education, and social service programs. The parents felt strongly that funding should not be based on grants or time limits.

TRANSITIONS

Solutions, Resources, and Partnerships for Improving Transitions

As in the other stages, improved communication during transitions was one of the most often cited needs, and parents repeated their suggestions of using 800 numbers for information clearinghouses and hotlines, especially for State program information, and creating local phone directories for resources or computer databases that would be updated yearly with current information on various programs. Some delegates noted that hotlines need to have bilingual operators who are representative of the calling population. One delegate commented, "Where's 1-800-MEDICAID? There's no trouble finding 1-800-SEX."

To address the need for culturally relevant programs and culturally sensitive staff people, the delegates suggested that professionals, particularly the first points of contact in a program or service, be given sensitivity training so they know how to avoid offending

people from various ethnic backgrounds, social classes, and financial means.

Parents said they could use guidance through the health, education, and social service systems. One such guide they proposed was using system veterans as mentors for new parents; these veterans could become personal mentors or could develop resource manuals that parents new to programs would receive for assistance and advice. They could also encourage new parents to seek out community-based groups, particularly support groups.

Doctors and hospitals could provide guidance to parents through expanded prenatal and parenting training. They could also distribute information and do outreach for State and community programs through packets that would be given to every parent of a newborn. Service providers could assign a full-time staff person to help people with transitions into and out of the program or service.

A number of regions discussed total community ownership of programs as another solution to promoting parental involvement. In other words, programs have to be familiar to everyone in the community, not just parents. It is also important to involve parents in evaluation teams for clinics, schools, and social service agencies.

The delegates found no shortage of solutions, either, for how to decrease paperwork and modernize programs. As was previously discussed, every work group advocated one-stop shopping, sensible hours that fit parent schedules, and the use of a single form for several assistance programs. Likewise, many parents proposed that one case worker be assigned to work with a family for all public assistance programs, rather than one worker for each program. This practice would allow families and case workers to develop a more trusting relationship and would reduce duplication of questioning and processing.

The delegates also offered more solutions to the problem of rigid eligibility standards. The delegates suggested that assistance programs base their decisions on take-home pay, not gross income. One mother said, "If I brought home my gross pay, I wouldn't need the services."

The delegates also suggested that the Government develop hardship deductions that would be used in calculating eligibility for services and programs. Another call was for a safety net for families who don't always fit within the parameters of assistance programs but are needful of help, even for a short time. An example of such a situation came from a southern delegate who told that she was living in the north when her doctor said her child was dying and needed to live in a warm climate. She and the child moved to Florida, but the father, who couldn't find a comparable job in Florida, stayed in Michigan. The woman applied for some assistance but was told she wouldn't be eligible unless she first filed abandonment charges against her husband.

All work groups discussed legislative solutions and regulatory relief to some of the barriers to successful transitions. One remedy, the delegates agreed, is that parents have to support and elect family advocates at all governmental levels. Another recommendation is for the Government to simplify application and eligibility requirements. A third solution involves getting parental leave bills passed; they have been proposed but now they must be enacted so that parents, especially poor working parents, can have time away from their jobs without being penalized when a child needs to see a specialist or go to an interview for a new educational program.

A number of delegates expressed concern that laws supporting families have been enacted but are not being enforced, at least not everywhere. Delegates from New York, New Jersey, and Puerto Rico, for instance, made a laundry list of needs that delegates from the Virgin Islands said their territorial government is addressing through the provisions and mandates in the Education for All Handicapped Act (Public Law 99-457), which targets children aged 0 to 2 who are at risk.

The parents did not let themselves off the hook as far as developing solutions was concerned. The parent-directed solutions included acting assertively on the child's behalf, teaching children their rights so they can become their own advocates, training them to be cooperative (even when others are not), helping them understand it's not their fault when difficult teachers or

caregivers can't be circumvented, and confronting teachers who don't respect children or who belittle them, especially in front of other children.

Programs *That Parents Grade A+*

When the delegates were asked to make a wish list of what a model program would be like, succinct descriptors were given quickly. In summary, the parents said programs must be child-centered and family friendly, be easily accessible, have broad eligibility standards, be antidiscriminatory and multilingual, be well promoted, provide individualized service, be staffed sufficiently, and have hours of service that are convenient to parents.

Parents also cited a number of programs that they felt were exemplary in their administration or service. Public Law 99-457, for children at risk aged 0 to 2 years, is a good example of a seamless and effective system. New parents need to be targeted for special attention. Public Law 99-457 should be expanded to benefit older children and children who do not have special needs, and should include family planning and prenatal and neonatal services. More vaccines could also be delivered through this program. Other generic programs, or those based in many States, included Head Start, school-based clinic programs, Home Instruction Program for Preschool Youngsters (HIPPY), workshops on the development of Individual Education Plans (IEPs), United Way services, Pathways to Understanding, and Family Resource Centers. Local or regional programs are listed in the descriptions of individual work groups, which follow.

The delegates offered these recommendations with the hope that many of them will be implemented. One parent concluded, "We've said all this before; is anyone listening?"

Regional Issues

REGION 1

CONNECTICUT

MAINE

MASSACHUSETTS

NEW HAMPSHIRE

RHODE ISLAND

VERMONT



Region 1 delegates stressed the importance of good prenatal care, family planning, neonatal screening, and early health intervention programs. To increase awareness of such programs, information on the programs should be available in public libraries. A catalog of available services, explaining eligibility criteria and benefits, would help

parents as they enter the systems. The delegates recommended that application processes be streamlined, beginning with a single application form, if possible, for all services. Application forms should be adapted to linguistic and cultural differences. The blind, the hearing impaired, and those with low literacy levels need special attention. Social service and health care providers need to adjust or stagger their office hours for working parents. The parents' transportation needs also should be addressed.

To participate fully in the health, education, and social services systems, the delegates strongly advocated that parents vote in national and local elections, join or form networks in their communities, and take a more active role in their school systems. They viewed advocacy for their children as a routine part of parenting in their relationships with teachers, doctors, etc., and not just in the realm of legislative activities. They stressed that service institutions need to be more flexible philosophically so that they can be more "parent driven" and that parents should

Region 1

Recommendations at a Glance

Awareness and Entry

- ★ Make information on health, education, and social services available in public libraries
- ★ Streamline the procedures to apply for services
- ★ Adapt application forms to linguistic and cultural differences
- ★ Offer flexible hours for services
- ★ Address transportation needs

Participation

- ★ Encourage parent participation and advocacy
- ★ Inform parents of their rights; publicize program policies and parents' options
- ★ Make service providers accountable
- ★ Understand the needs of parents, particularly single parents

Transitions

- ★ Determine readiness for transition by abilities and developmental stages rather than by age
- ★ Maintain consistent philosophies among programs
- ★ Train parents in the curriculum being used and demonstrate ways to supplement it
- ★ Train providers to be sensitive to differences in ethnic, financial, and social status

participate with schools and service providers as respected partners. For instance, parents should be allowed to attend in-service training sessions for service providers, and they should serve on boards that direct the activities of programs. Parents should be informed of their rights as they participate in the systems; i.e., policies and options should be not only written but also publicized. Policies that result in children being taken from their parents should be scrutinized closely. Parents should not be afraid to express their needs. The delegates also complained that social service and health care systems are rigid, bureaucratic, and overspecialized, with the result that parents feel lost within these systems. The delegates were concerned that the service providers are not accountable for the quality of service they provide. Parents need support from the systems and from their employers (e.g., flexible hours) to participate. Providers and employers must recognize that parents, particularly single parents, can't "do it all"; they have physical and emotional limitations (such as lack of time and an abundance of stress).

Parents from the New England States were concerned that children are subjected to transitions too often simply because their age dictates they move into a new program. These delegates felt that instead of chronological age, abilities and developmental stages should be the factors that determine readiness to move on, up, or out. They noted that this concern is especially important for children with special needs. Another concern peculiar to this group was that changes in philosophy among programs impede successful transitions. As a solution, they suggested that schools host parent workshops that demonstrate the curriculum and tell parents how they can complement it at home. Region 1 delegates echoed the sentiments of most other groups concerning how programs and people must be sensitive to differences in ethnic, financial, and social status. But this group added a unique parental role to the equation: Mothers and fathers must make sure that caregivers and service providers understand and appreciate individual family values, as well.

Among the model programs in the New England States that the delegates cited are Elliot's Healthy Kids



in New Hampshire, which coordinates nutrition education in schools; the Upper Valley Support Group in New Hampshire and Vermont; Growing Up OK in Bristol, Vermont; Early Childhood Group in Middlebury, Vermont; Collaboration for Children in Massachusetts; Early Childhood Network in Aroostook, Maine; Developing Capable People Transition Task Force and Child Find, both in Rhode Island.

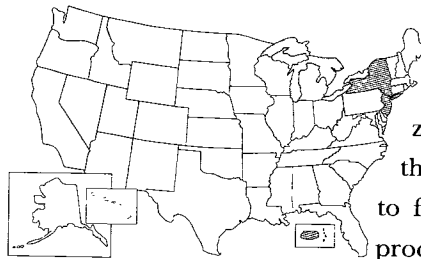
REGION 2

NEW JERSEY

NEW YORK

PUERTO RICO

VIRGIN ISLANDS



Region 2 delegates said that parents entering health, education, and social service systems should network with more experienced parents and play active roles in parents' organizations. The delegates also advised that resource coordinators be assigned to families to help simplify the entry process and assist the parents as they learn about and access the programs they need.

Application and entry procedures are far too daunting; parents can feel lost trying to enter the system. One-stop shopping for services was strongly recommended. Office hours must be built around the needs of working parents. In addition, agencies need to expand their public service announcements and make a greater overall effort to keep parents informed about available resources. The delegates recommended a toll-free information hotline, along with support groups and other programs designed to make parents, especially teenage parents, more aware of their responsibilities.

The Region 2 delegates felt that the parents' role in networking does not end with active participation in the systems. Parents should enlist other families into programs. The delegates also agreed that parents should have a stronger role in developing agency procedures and policy. Parents need greater representation on agency advisory boards. Parents also should be involved in reforming health, education, and social service systems to benefit families. For instance, the delegates cited numerous problems with Medicaid, such as lack of physicians who accept Medicaid and long waiting lists for those who do. In addition to needed reforms in services, the delegates cited a need to change our society's attitude toward families receiving assistance from the systems. They are stigmatized in the public's perception as lazy and uncaring, and even the social service workers often behave rudely toward parents. This situation causes high frustration levels for families who participate in programs and prevents others from participating. The delegates felt that this behavior by service providers is a symptom of employee burnout, and recommended that employees be rotated

Indicating their commitment to finding solutions to the problems discussed, the Region 2 delegates held an impromptu meeting on their own time to outline a proposal for establishing a model health, education, and social service system. The proposal calls for a Federal initiative mandating a partnership across Federal agencies, the Office of Management and Budget, key Congressional committees, and families representing local areas. The initiative would establish a formal structure for implementing the following principles at all local levels:

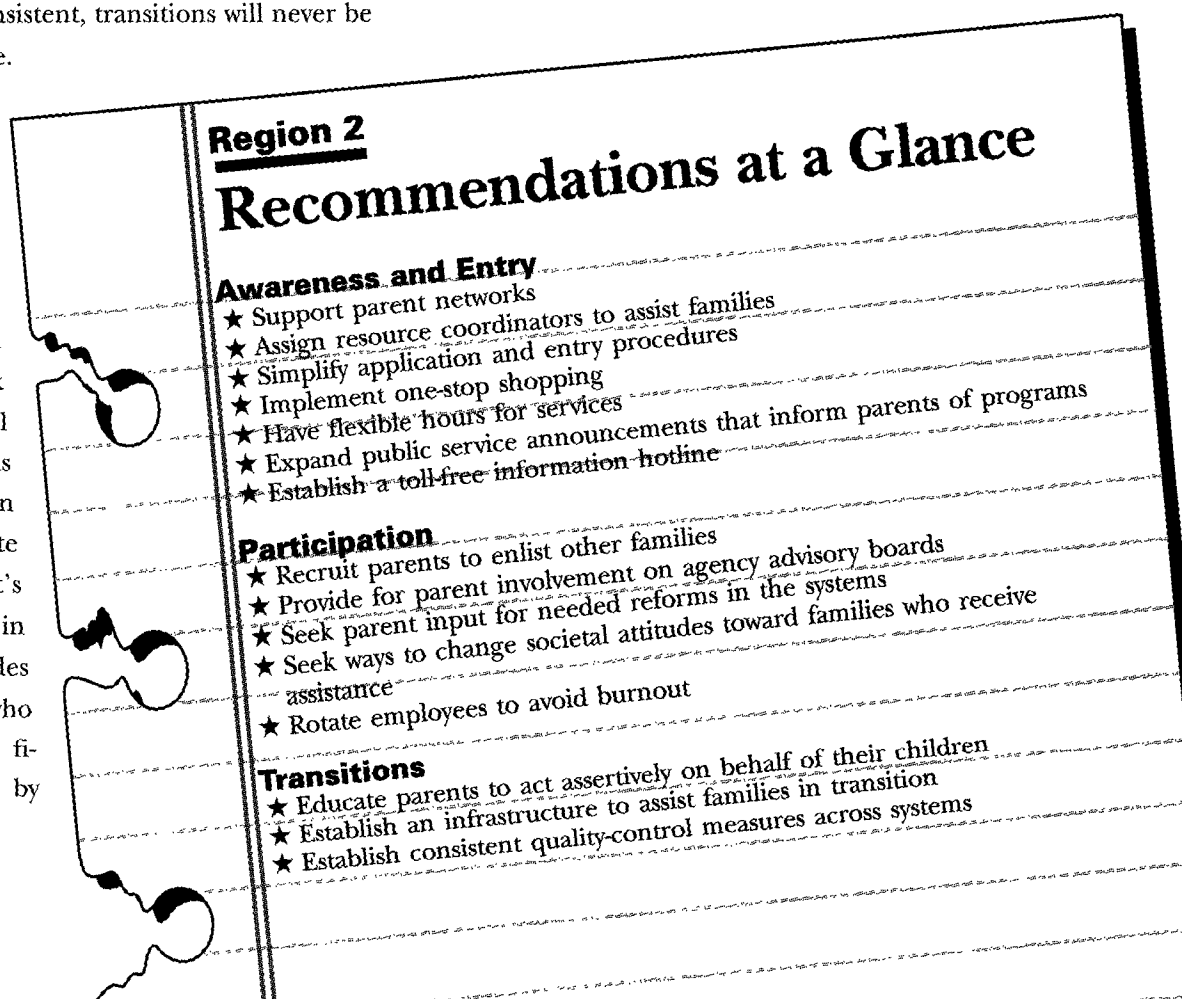
- ★ A client- and family-centered program philosophy that emphasizes parent involvement in children's programs, and that is accountable to the individuals served.
- ★ A creative and flexible atmosphere within the systems brought about by regulatory relief from bureaucracy and "red tape."
- ★ The standardization of eligibility requirements across all service programs and simplification of the process for establishing a client's eligibility.
- ★ Easier access to services provided by centralized directories of services, one-stop shopping, and flexible hours.
- ★ An integrated approach to service delivery using unified case management and followup.
- ★ The rotation of service personnel and continuous training and cross-training to reduce burnout and promote sharing of information across programs within the systems.
- ★ Increased parental community involvement. Parents could make valuable contributions, especially for public relations, outreach to new families, and advertising of services. To promote parent involvement, use a community-based approach and allow for flexible work schedules. Seek collaboration with businesses, churches, and other community organizations.

to different positions within their agencies on a regular basis. This solution would also provide employees with a wider range of experience and information about how their agencies work—information that they can pass on to parents.

Delegates from Region 2 considered the parent's role in transitions as acting assertively or aggressively and emphasized that it must begin as soon as a child's needs are diagnosed. It is the parent's responsibility, they said, to demand access to and information about the prenatal and postpartum care their child with special needs might require. However, to encourage parents to act assertively, they agreed, the Nation must develop effective parent education. That education is linked to another need cited by Region 2 delegates. They wanted the Surgeon General to know that the country needs to establish an infrastructure to assist parents through their children's continuous transitions. Another important issue to this group was the lack of quality control in services. They remarked that unless quality control in health, education, and social service systems is consistent, transitions will never be better than mediocre.

Puerto Rico's Project ESPA (Escuela Para Padres Adultos, Project School for Adult Parents) was singled out as a successful parents' support group. The New York Foundling Hospital was also mentioned as a model program. In New Jersey, the State Health Department's Catastrophic Illness in Children Fund provides grants to families who would otherwise be financially devastated by catastrophic illness.

In addition, the Region 2 delegates recommended establishing a Federal initiative to institute a formal structure for implementing several principles in health, education, and social service systems. In implementing this initiative, the Region 2 delegates recommended the following approach: (1) linking it to America 2000 or similar program; (2) involving the private sector; (3) borrowing strategies that work from existing model programs and integrating them vertically and horizontally into community programs; (4) designating the Surgeon General to head the initiative and enlist the participation and cooperation of all relevant Federal agencies; and (5) recruiting parents who represent the diverse communities of the United States to be the liaison between government, community, and business representatives in the initiative. The delegates recommended recruiting and organizing these parents through a national clearinghouse and compensating them as experts for their work on the initiative.



Region 2

Recommendations at a Glance

Awareness and Entry

- ★ Support parent networks
- ★ Assign resource coordinators to assist families
- ★ Simplify application and entry procedures
- ★ Implement one-stop shopping
- ★ Have flexible hours for services
- ★ Expand public service announcements that inform parents of programs
- ★ Establish a toll-free information hotline

Participation

- ★ Recruit parents to enlist other families
- ★ Provide for parent involvement on agency advisory boards
- ★ Seek parent input for needed reforms in the systems
- ★ Seek ways to change societal attitudes toward families who receive assistance
- ★ Rotate employees to avoid burnout

Transitions

- ★ Educate parents to act assertively on behalf of their children
- ★ Establish an infrastructure to assist families in transition
- ★ Establish consistent quality-control measures across systems

REGION 3

DELAWARE

DISTRICT OF
COLUMBIA

MARYLAND

PENNSYLVANIA

VIRGINIA

WEST VIRGINIA



Region 3 delegates underlined the importance of special programs for teenage parents to help them cope with their role as parents and to make them aware of available services. They also expressed that entry into programs would be facilitated by barrier-free health care centers and resource coordinators for special needs children. To

inform parents about available services, lists of services could accompany birth certificates; private doctors should always have such lists on hand. The special needs of foster children demand greater attention; medical charts and equipment for foster children with special needs should follow the children in a timely manner. Family leave would allow parents time not only to address their own infants' special health needs, but also to help other parents and their children. While all regions discussed legislative solutions and

regulatory relief to some problems families face, Region 3 delegates were the only ones who discussed supporting the fetal alcohol bill as part of the solution to making healthy children ready to learn. This bill would prohibit restaurants, bars, and liquor stores from selling alcohol to pregnant women. Also, because support groups are so important, funding should be provided to sustain them and cover basic operating costs. Additional funding is required to prevent turf battles among agencies and within the communities they serve.

Region 3

Recommendations at a Glance

Awareness and Entry

- ★ Establish special programs for teenage parents
- ★ Establish barrier-free health care centers and provide resource coordinators for special needs children
- ★ Distribute lists of services with birth certificates
- ★ Pass a family leave bill
- ★ Pass the fetal alcohol bill
- ★ Provide funding for support groups
- ★ Expand program funding to prevent turf battles among various programs

Participation

- ★ Make programs community based
- ★ Hire recipients of services to help administer services
- ★ Allow parental involvement in policymaking
- ★ Reform programs to increase sensitivity, provide better training for service providers, make better use of resources, decrease bureaucracy, and disseminate information more effectively
- ★ Create tax credits for parents who keep children with special needs at home
- ★ Create tax benefits for employers who hire persons with special needs or the parents of children with special needs
- ★ Make funds available for affordable daycare

Transitions

- ★ Invest in preventive services
- ★ Promote continuity of services among the systems
- ★ Resolve problems on a systematic basis rather than a case-by-case basis

To enhance participation in the systems, the Region 3 delegates stated that programs should be community based whenever possible, administered by people who live in the communities. The delegates also recommended that the recipients or part-time recipients of services be hired to administer the services as well, to help bridge the gap between bureaucracies and families. They viewed the role of parents participating in the systems as that of decisionmakers who help empower families receiving services, although they admitted that the systems do not allow for parental involvement in policymaking. They were most concerned about the lack of cultural sensitivity displayed by the systems, lack of training for service providers, and the negative stereotyping of recipients of services. They also complained about the systems' bureaucracy and the poor use of resources, resulting in the lack of services in some areas, and the lack of information about services. The delegates from the mid-Atlantic States advocated financial solutions to parents' needs. They suggested creating tax credits for parents who keep children with special needs at home (rather than institutionalizing them at Government expense), creating tax benefits for employers who hire individuals with special needs or their parents, and making funds available for affordable daycare.

The Region 3 delegates maintained that transitions would be facilitated if programs focused on prevention of problems before crises occur. Although preventive services may require a higher initial investment, these parents asserted, they would present significant cost savings to the Government in the long term.

They also commented that there is a lack of continuity of services as transitions are made within the systems. Delegates told how some children with special needs were given assistive devices to help them in school but that the equipment remained the school's property. In some cases, the equipment was not even allowed to leave the building when the child went home for the evening; even more often, a child was not allowed to take the devices to a new school—even one in the same system—as he or she matriculated. The delegates warned that these policies do not promote smooth transitions for parents or children. A father

from Pennsylvania was able to add some hope to this discussion when he told how his State had bypassed the problem with a solution that benefitted everyone. In his State, parents of a child with special needs can spend up to \$1,500 annually on assistive devices such as reading boards. The parents buy the device, but are reimbursed by the State. Their child can use the item until he or she outgrows it or leaves the State school system. Then the equipment is returned to the school, where it becomes available to another child.

This regional group also advocated that solutions must be systemic; programs and services cannot continue to respond to problems on a case-by-case basis. One parent said her child's school had rerouted a bus so it could transport a child with disabilities. But that change in the route meant that some children rode the bus 4 hours a day. The school responded to a particular case, not the underlying problem that it did not have enough buses accessible to children with disabilities. When another child with disabilities needed transportation, the problem had to be readdressed. The parents maintained that the school system should have broadened its solution the first time by buying another bus and hiring another driver, a solution they felt would be cost effective in the long run.

Model programs cited by the Region 3 delegates include Pennsylvania's Development Disability, which funds support groups, and the Communication Council, which involved parents as it rewrote the State-level standards for special education; the District of Columbia's Equipment Loan program, which funds equipment for special needs children, and the Parents and Friends of Children with Special Needs, a parent support group; Maryland's Special Mothers in Training, a 5-week training program for parents with disabilities, and New Visions, a program that uses parents as case managers; West Virginia's Public Health Screening, designed to meet the needs of parents who do not qualify for Medicaid but cannot afford health insurance; corporate Adopt-a-School programs; and Virginia's Department of Education/Division of Special Education Programs, which provides information on child development.

REGION 4

ALABAMA

FLORIDA

GEORGIA

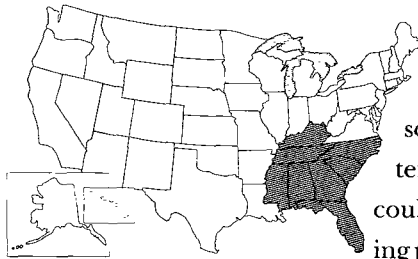
KENTUCKY

MISSISSIPPI

NORTH CAROLINA

SOUTH CAROLINA

TENNESSEE



Region 4 delegates advocated that all Federal programs share a universal, easy-to-read application form to help simplify the entry process for parents. A central community resource clearinghouse, or referral center, supplemented by a toll-free hotline, could also facilitate the process for entering parents. The eligibility criteria should

be the same for all programs, but they should be more flexible. Presently, the systems encourage "staying poor" to meet these rigid criteria. They stressed that incentives are needed for families to move beyond assistance. The delegates also recommended that education in parenting skills begin in junior high school.

Overall, the systems would be more responsive to parents' needs as they participate in programs if the parents had greater involvement in policymaking and

especially in the training of providers, many of whom behave as though they have no sense of the worth and dignity of needy families. These families face language barriers, attitudinal barriers, physical barriers at health care centers, long distances to the centers, and inflexible office hours. Working parents need special consideration. As a rule, the parents have no choice but to adapt to the systems' requirements, whereas, as one parent said, "The money should follow the child, not the other way around." They expressed a need for professionals who know the community, its resources, and the issues

Region 4

Recommendations at a Glance

Awareness and Entry

- ★ Develop a universal application form and simplify the entry process
- ★ Establish community resource clearinghouses, supplemented by a toll-free hotline
- ★ Establish flexible eligibility criteria and incentives for families to move beyond assistance

Participation

- ★ Involve parents in policymaking and training of service providers
- ★ Remove barriers of language, attitudes, physical limitations, distances, and limited hours
- ★ Provide professionals who know the community, its resources, and the issues facing families
- ★ Provide job stability and affordable housing
- ★ Establish family leave policies
- ★ Provide better daycare and respite care services

Transitions

- ★ Involve parents in peer group visitation programs
- ★ Allow family time to reassure children during transitions



facing families. The delegates stressed that job stability and good housing are critical components of health. Parents need family sick leave policies and release time to obtain the services they need. Housing ordinances need to be enforced. Also needed are better daycare services and respite care services for overburdened parents.

Several regions considered some untraditional ways to improve communications to facilitate transitions. Region 4 delegates made a unique recommendation: Involve parents in peer group visitation programs. One mother told how her community solicits experienced parents to visit the homes of new parents and offer friendly, nonthreatening advice about programs, services, support groups, and organizations that are available to them. These visits, she added, are made to all new parents, not just parents of children with special health, education, or financial needs. The parents from the southeastern States also pointed out the importance of families' making time for children between transitions; everyone needs a break, they said, especially when a transition involves a change in marital status, living arrangements, or health care.

Some model programs cited by the Region 4 delegates include Kentucky's Family Resource and Youth Service Centers, created as part of the Kentucky Education Reform Act and operated through the schools to benefit children and families at risk; the Eastern Kentucky Child Care Coalition, a private resource development agency that offers training and assistance to childcare providers and families; and Mississippi's Families as Allies, a network of families with special needs children. The Florida delegation shared materials on several public and private programs from their State: Infants & Toddlers; Florida's Interagency Program for Children and Their Families, which has established the Directory of Early Childhood Services, accessible through an 800 telephone number; Collaborative Adolescent Parenting Program (CAPP), an intergovernmental, interagency, community-based effort to support teenage parents; Family Connections, which provides services to low-income teenage parents, and Family Interaction Now (FIN), a family support program for recovering pregnant and postpartum addicts, both sponsored by the Child Care Connection of Broward County, Inc., a private, nonprofit organization that supplies Title XX childcare; Casa Madonna, an aftercare program for Hispanic substance-abusing mothers, which is sponsored by the Miami Mental Health Center, Inc.; The Bridge, sponsored by Family Health Services, Inc., which provides a mix of services to young mothers and their children; and Project MITCH (Model of Interdisciplinary Training for Children with Handicaps), which provides training to parents and other care givers, through funding from the Florida Department of Education to the Florida Diagnostic and Learning Resources System/South. In addition, the Department of Health and Rehabilitative Services sponsors First Steps and the Community Resource Mother or Father Program.

REGION 5

ILLINOIS

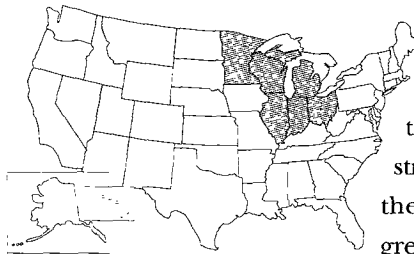
INDIANA

MICHIGAN

MINNESOTA

OHIO

WISCONSIN



Delegates from Region 5 agreed that parenting skills should be part of every child's schooling and that resources should be available for the continuing education of parents in these skills. Better parents will become a stronger and more effective presence in their communities. They will assume greater responsibilities in their local school systems, both in policymaking and in day-to-day participation, to help counter the chaotic forces that act on children as they enter adolescence. The Region 5 delegates complained that the middle class is excluded from services. They stressed that everyone needs access to adequate health care and that our Nation should provide "equal education for all." They pointed out that the goals of the Surgeon General's initiative should go beyond the year 2000. Other barriers to entry into the systems that

they cited are long waiting lists for services and inflexibility of the systems. They recommended a one-stop-shopping approach to services with providers who are informed about available resources. They suggested producing a guidebook of services and including a directory of local services in every community's telephone directory.

As families participate in programs, the delegates asserted, education should accompany the services rendered. They complained that the programs are not family centered, and that parents who act assertively to have their needs met are isolated. The social

Region 5

Recommendations at a Glance

Awareness and Entry

- ★ Provide training in parenting skills for all children
- ★ Don't exclude the middle class from services
- ★ Continue the Healthy Children Ready to Learn Initiative beyond the year 2000
- ★ Implement one-stop shopping
- ★ Produce a guidebook of services and include a directory of local services in community telephone directories

Participation

- ★ Accompany services with education
- ★ Provide mechanisms for parents to get answers for questions or to voice complaints
- ★ Allow greater parent involvement in policy decisions
- ★ Forge stronger links among schools, social service systems, and local business
- ★ Prioritize needs before spending funds and make programs accountable for how funds are spent
- ★ Provide for unbiased evaluation of programs
- ★ Address the causes of families' problems and provide healing, not "band-aid fixes"

Transitions

- ★ Teach basic life skills, beginning at an early age, to prepare children to parent the next generation
- ★ Support parent networks and outreach programs
- ★ Appoint Dr. Novello as the Administration's advocate for families

HEALTHY CHILDREN Ready to Learn



service system was criticized for having no built-in mechanism by which parents can get answers to their many questions and a sympathetic ear for their complaints. The systems are generally perceived as bureaucratic, rigid, and insensitive. Parents need to play a greater role in policy decisions and act as advisors to programs. For instance, many of the delegates felt that parents should work with their schools to explore the possibility of dress codes and establish other policies. When this group discussed the parental role of being an advocate, they commented that parents need to take this responsibility to the fullest. They must be involved in the school or program, know everyone from school board members to administrators to teachers, and become a presence in their child's education. Schools, in turn, need to forge stronger links with the social service systems and local businesses. Another important issue to the Region 5 delegates was that needs must be prioritized before money is spent, that programs must be accountable for how the money is spent, and that programs should be evaluated by unbiased parties. The delegates expressed that programs must address the underlying causes of problems families face and that services should provide healing as families participate, not give them just a "band-aid fix."

The Midwestern delegates repeatedly said that parents need to begin at childhood to prepare their children for the ultimate transition from child to parent. They advocated reaching out to children to show them how to be parents and to explain the responsibilities that go along with the role. They recommended that schools teach basic life skills, beginning at an early age, so that children will be prepared to parent the next generation.

These parents also stressed that communication among parents and between parents and programs is key to successful transitions. They stated that strategies to improve communication should include outreach programs to draw new families and to truly affect the community. Region 5 delegates looked to the Surgeon General to be more than a partner with them in making healthy children ready to learn. They agreed that she must be the administration's advocate for families. She must be among the ranks of people who hold health, education, and social service systems accountable for ensuring that children and parents can make transitions between programs smoothly.

Model programs cited by the Region 5 delegates include the Illinois Governor's Education Initiative, which involves parents in school policy decisions. Under this program, 35 communities discussed the reallocation of funds to allow State agencies to coordinate their efforts and develop stronger ties with the school system. Another Illinois program, Families With A Future, funds prenatal care, home visits, a children's clinic, nursing care, and certified advisers who coach mothers as they enter the social service system; volunteers provide transportation. In Minnesota, the Leave No Child Behind program funds learning readiness. Other programs in Minnesota include Challenge 2000, Parent Involvement, and Learning Readiness. The Ohio delegates cited Family and Children First, and Indiana parents praised the Indiana University Medical Center's James Whitcomb Riley Children's Hospital as a model for caring for sick children and supporting the families during times of crisis. Michigan programs include the Latino Outreach Program in Detroit and Project Uptown.

REGION 6

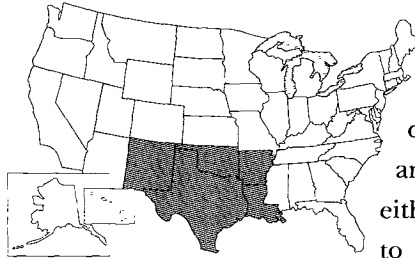
ARKANSAS

LOUISIANA

NEW MEXICO

OKLAHOMA

TEXAS



Region 6 delegates asserted that families should be a nationwide priority. They also strongly advocated regulation of the insurance industry. Insurers can raise rates, deny coverage, and cancel policies arbitrarily, with the result that families either cannot afford health care or have to enter the social service system and sometimes give up jobs and income to meet rigid eligibility criteria. The delegates also pointed to low levels of private participation in health care services, saying that if providers were reimbursed at competitive rates, the services would improve across the board. The providers need to be better informed about available services and ready to pass that information on to families. A resource directory and a toll-free information hotline in each State were strongly recommended.

In addition, health care providers should be coached and sensitized by parents who are participating in and have experience with the systems. At present, families are not perceived as partners with providers and do not feel respected. The delegates warned that parents with regional accents have to be careful that they are not perceived as less intelligent merely because their pronunciation is different or their speech patterns are slower. The point of contact for services (both for parents entering the systems and those already participating) should be an individual who is

Region 6

Recommendations at a Glance

Awareness and Entry

- ★ Regulate the insurance industry to prevent arbitrary cancellation of health insurance policies
- ★ Encourage private participation in health care services by reimbursing providers at competitive rates
- ★ Provide better informed service providers
- ★ Develop a resource directory and establish a toll-free hotline

Participation

- ★ Recruit parents to coach health care providers in sensitivity
- ★ Provide individuals who are representative of the community to be the point of contact for services and evaluation of programs
- ★ Orient services around family needs by locating facilities together in convenient locations
- ★ Allow parents more creative input and policy input and the opportunity to evaluate programs

Transitions

- ★ Maintain effective communication between parents and caregivers, particularly for foster parents
- ★ Provide mainstreaming for children with special needs in all communities
- ★ Form partnerships among agencies that provide health and medical care to better serve families



representative of the local community. Services are not oriented around family needs; families have to travel long distances to appointments because of the limited number of providers in these States, and then they are forced to wait and waste time. Services should be located as near families' homes as possible. Why not set up on-site facilities so that parents can attend to other important family business, such as doing laundry? The delegates insisted that parents need more creative and policy input into the systems and should be given the opportunity to submit evaluations of providers.

There was national consensus that successful transitions begin at home, but Region 6 delegates States added the advice that some situations demand special efforts. They commented that foster parents must be careful to validate their children's feelings at all times. Foster children have an extraordinary need to develop their self-esteem. Without this esteem, the parents said, children will not get the maximum benefit from transitions. Communications with children and caregivers has to be two-way. While it is imperative that parents be vocal advocates for their families and recognize their power as parents, these delegates agreed, it is also

critical that they listen to the children and the professionals taking care of them. Parents in Region 6 also pointed out that mainstreaming is not available in all communities, but it is a universal right of children to be allowed to mainstream. Parents, they said, need to demand this right for their families. The Region 6 delegates stressed that access issues must be addressed and that agreements are needed among agencies to form health and medical partnerships to better serve our Nation's families.

The Children's Hospital in Arkansas, which already has a hotline, was cited as a model program. Other Arkansas programs include Arkansas Better Chance, Child Find, Children's Medical Services, and Focus in Blytheville. Adult Learning Center in Shreveport, Louisiana, combines infant care, literacy training, and a welfare office. Dallas, Texas, has a quality infant care program for teenage mothers and helps them with the transition to Head Start. Another Texas program cited was the Childcare Management System in El Paso. Oklahoma programs include the Institute for Child Advocacy, Sooner Start, and Oasis.

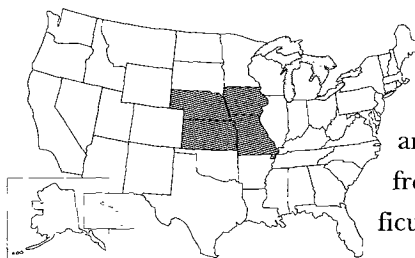
REGION 7

IOWA

KANSAS

MISSOURI

NEBRASKA



Long distances to health care centers are a problem in this part of the Midwest, and the quality of services is uneven in urban and rural areas. The lack of coordination among services forces parents to make frequent visits, compounding their difficulties. Eligibility requirements are inconsistent from State to State, and parents

who relocate in new communities have to repeat the lengthy application process. Because information on services is lacking, in Missouri, some neighbors go door to door with flyers and other information.

As families participate in programs, the Region 7 delegates recommended that parents seek an ally who can be relied upon to supply accurate information. In turn, parents should share their knowledge of the programs with others. Parents also have a responsibility to establish a positive interaction with the caseworker to give feedback

on the services received. In developing these relationships, however, they warned that parents must keep their first priority and maintain a balance between participation in program activities and family life. They feared that parents might fall into the trap of trying to do everything and warned that providers should not overwhelm parents with too much information and too many activities at the same time. Parent involvement in program planning would help prevent these problems, they said, and parents also should help set goals for the programs.

Region 7

Recommendations at a Glance

Awareness and Entry

- ★ Reduce distances that families must travel for services
- ★ Improve consistency of services from urban to rural areas
- ★ Improve coordination of services
- ★ Make eligibility requirements consistent from State to State

Participation

- ★ Promote parent support groups
- ★ Don't overwhelm parents with too many activities
- ★ Involve parents in program planning
- ★ Provide more year-round programs
- ★ Provide full-day Head Start or locate Head Start together with Title XX or other childcare programs
- ★ Provide childcare for special needs children

Transitions

- ★ Seek information from parents about children's specific needs
- ★ Provide honest answers to parents' questions rather than "beating around the bush"
- ★ Develop a national policy modeled after the Nebraska Family Policy Act
- ★ Promote partnerships, including parent-to-professional groups, professional-to-professional groups, agency-to-agency collaborations, community-to-community partnerships, and State-to-State partnerships

The Region 7 delegates expressed a need for more year-round programs for their children. They also suggested full-day Head Start programs or collocating Head Start with providers of Title XX or other childcare programs. They would like to have childcare available for their special needs children so that they can attend activities in which their "normal" children are involved. They described how special needs children are often denied activities simply because they are labeled as disabled, even though the parents think they are capable of participating. For example, one mother shared that her child was not allowed to ride a horse even though her husband was planning to ride with the child and take full responsibility for the child's safety. They urged that we "put labels on cans, not on children."

Like delegates from other regions, these parents said that, to ensure smooth transitions, they must be good recordkeepers and make sure their children's needs are communicated when records are transferred. Because those needs are not always part of an official record, parents must alert professionals to them. For example, health care professionals may be proficient at doing G-tube feedings, but a parent may be the only one to know that his or her child needs to be fed for 10 minutes, then rested for 10 minutes, before finishing the feeding. Caregivers might know how to get a child ready for bed, but parents know which children won't go to sleep without their teddy bears in hand. At the same time, caregivers need to communicate fully with parents. These parents prefer honest answers to their questions. They insisted that caregivers should "tell it like it is" and not "beat around the bush," particularly when the information concerns their children.

The delegates agreed that a model program would have a single point of entry even though a family might need a dozen or more services. The model program would cover all needs and disabilities and be based on the philosophy that the systems should adjust to the needs of the family. There would be a single set of paperwork for all services and a resource coordinator assigned to each family to help the parents through the bureaucratic maze. Prescreening of infants and Child Find services should be made available to all parents.



They cited the Nebraska Family Policy Act, which coordinates all services to needy families, and recommended that a national policy modeled after this act be developed. These delegates also expanded the idea of parent support groups and partnerships to include parent-to-professional groups, professional-to-professional groups, agency-to-agency partnerships, community-to-community partnerships, and State-to-State partnerships.

Kansas' model programs include Parents as Teachers, Healthy Start, the Parent Training and Information Center, and Keys for Networking, all in Topeka. In Omaha, Nebraska, the First Step Infant Health Care Project has prenatal programs and integrated services for low-income mothers living in public housing. Under Missouri's First Steps program, resource coordinators come to the home and explain available services to parents. In St. Louis, Missouri, the Human Development Corporation, Parents as First Teachers, and the Parent/Child Center were recommended. Missouri and Nebraska each have information hotlines: In Missouri the hotline is called Parent/Link. Kansas also has a Resource and Referral System hotline. The Nebraska Family Support Network was cited as a model support program. Missouri's Parkway Early Childhood Programs and Early Childhood Organization (ECHO) are successful model programs. Iowa has the Early Childhood Special Education program, the Parent Infant Nurturing Center, the ARP Respite Care Training Project, and Up With Families.

REGION 8

COLORADO

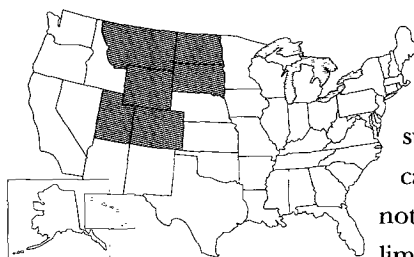
MONTANA

NORTH DAKOTA

SOUTH DAKOTA

UTAH

WYOMING



Delegates from these western States were concerned about the availability, quality, and cost of health care in America. They pointed out that getting families covered with health insurance is a need and a solution. They cautioned that health insurance should not be confused with Medicaid, which is a limited resource. In comparing Medicaid

with health insurance, they pointed out that health insurance allows access to health care; Medicaid does not guarantee that access. Health insurance covers preventive care; Medicaid does not. Going hand in hand with the problem of health care costs is the concern that liability has become a real problem in the United States. The doctor's fear of being sued for damages is increasing costs for parents and communities.

These more sparsely populated States have several problems in making families aware of services and

enlisting their participation. Families living in rural areas often have to rely on word-of-mouth for information on available services: A toll-free hotline would be a useful solution. Each State should have a free clinic system with an interagency coordinator to provide parents with information and help line up State services.

Region 8 delegates also urged greater involvement at the community and local level, not only for individuals but also for local businesses. They recommended that local business leaders

Region 8

Recommendations at a Glance

Awareness and Entry

- ★ Provide affordable health care for all families
- ★ Establish a toll-free hotline
- ★ Establish a free clinic system with an interagency coordinator

Participation

- ★ Encourage support from local businesses for programs such as childcare
- ★ Extend programs such as Girl Scouts and 4-H Clubs to all communities and provide funds for families who can't afford to participate
- ★ Involve parents in program design and planning
- ★ Involve parents in programs to visit new mothers and serve as their mentors
- ★ Expand hospital funding to provide followup care

Transitions

- ★ Seek information from parents about mechanisms that trigger certain behaviors in children
- ★ Provide training in parenting skills and nutrition as part of the basic school curriculum
- ★ Encourage religious bodies to conduct parenting training and help parents build a positive parenting vision
- ★ Encourage Americans to become a nation of learners
- ★ Mingle Federal, State, and local funds to support programs
- ★ Run programs as businesses are run, with measures to ensure that their objectives are being carried out



support childcare centers, for instance. They suggested that community programs such as the Young Men's Christian Association (YMCA), the Girl Scouts, and 4-H Clubs be extended to all communities and that funds be provided to families who cannot afford these programs. They recommended that parents lobby within their communities to sensitize leaders to the importance of the family as the basic building block of the community. They stressed that parents should be involved in program design and planning. An example of veteran parent involvement would be to visit new mothers in the hospital and serve as mentors. They also stated that hospitals need to allocate funds for followup care.

Like the parents from Region 7, the Region 8 parents said that it is their role to inform programs about their children's particular behaviors and needs that might not be part of an official record. These delegates talked about the importance of informing new service and care providers, before the transition takes place, about trigger mechanisms that evoke certain behaviors and ways the parent has found to control behavioral problems. Transitions can be difficult and become a monumental hurdle to a family's development. When a transition is made, these delegates said, families need to celebrate their mutual or individual achievement.

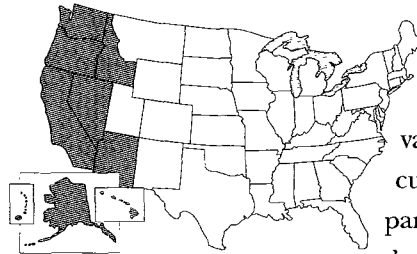
The Region 8 delegates advocated that training in parenting skills and proper nutrition should be part of

the basic school curriculum. Furthermore, they maintained that parental education is a role that religious bodies should assume. Part of that education, regardless of its source, should be to help parents develop a positive parenting vision. It would be wise for educators to remember that not every parent's childhood lends itself to such positive experiences and that not everyone has an instinctive vision about parenting. This group looked at education in America and declared that we must become a nation of learners. Parents need to redevelop their own enthusiasm for learning if they are going to create such an enthusiasm in their children. The Region 8 delegates cited a need for more mingling of Federal, State, and local funds to support programs. They also added that programs should be run in a manner similar to businesses, with measures to ensure that those who use the programs are receiving the value that they are intended to provide.

Existing model programs they cited were Partners in Leadership, Family Resource Centers, Effective Parents Project, Parent Education and Assistance for Kids (PEAK) Parent Center, the Disability Information and Referral Service (DIRS) Hotline, Connect, and El Groupa Vida in Colorado; Ask A Nurse and First Steps in Montana; Tracking in North Dakota; and Baby Your Baby in Utah.

REGIONS 9 AND 10

ALASKA
AMERICAN SAMOA
ARIZONA
CALIFORNIA
GUAM
HAWAII
IDAHO
MARIANA ISLANDS
NEVADA
OREGON
WASHINGTON



Region 9 and 10 delegates argued forcefully that health care and social service systems should recognize and value native language differences, local customs, and family values. Most systems show a marked cultural insensitivity and fail to involve parents in decisions that affect their children. Social service workers need to be

more compassionate, and they need to encourage the growth of community-based programs. Eligibility criteria need major overhauling. The criteria are based on artificial standards (income levels versus need) and lead to unfair labeling and inequities in services. Regional cost of living differences are not taken into account. They maintained that families who need the services most often cannot participate.

Like parents in other regions, these delegates complained about the lack of coordination of services; duplication of some services confuses recipients and forces providers to compete for funding while gaps exist in the provision of other services. Furthermore, they maintained that the distribution

of services around the country is uneven. They also voiced a desire to participate in the design and planning for programs, including involvement in curriculum development, hiring, and budget decisions. At the same time, parents must ensure that service providers have a full understanding of their children's needs. They also maintained that the parents have a responsibility to be advocates, not only for their children but also for the programs in which they participate, and to lobby for these programs.

The delegates from the Far West and

Regions 9 and 10

Recommendations at a Glance

Awareness and Entry

- ★ Recognize and value cultural differences
- ★ Involve parents in decisions that affect their children
- ★ Overhaul eligibility criteria, basing eligibility on need rather than income and considering regional cost-of-living differences

Participation

- ★ Improve coordination among programs
- ★ Distribute services more evenly throughout the country
- ★ Involve parents in program design and planning
- ★ Encourage parent advocacy

Transitions

- ★ Help fulfill basic needs such as housing and health care
- ★ Improve collaboration among agencies and consistency across agencies
- ★ Provide referral persons within agencies to help families deal with transitions
- ★ Increase public sensitivity to family problems such as divorce, substance abuse, unemployment, or incarceration of a parent

Pacific protectorates shared their concerns about the overwhelming responsibilities of being parents. They said that parents need hope to get them through daily living and especially in situations when transitions are involved. To give families hope, Government agencies and other service providers need to help them fulfill basic needs, including those for housing, health care, and nutrition. These parents also noted the lack of collaboration among agencies and the lack of consistency across agencies, both of which make transitions more difficult. They cited a need for referral persons within agencies to help families deal with transition issues. The Nation as a whole (especially all people caring for its children) needs to comprehend the effects of such family problems as broken homes and substance abuse; special concerns of parents who are incarcerated or unemployed need to be understood and taken into consideration when transitions are necessary. Parents have a responsibility to network and to be team players in helping to provide services, particularly during times of transition. Like the delegates

from other regions, this group maintained that parents must maintain information about their children, and they must prepare their children for transitions.

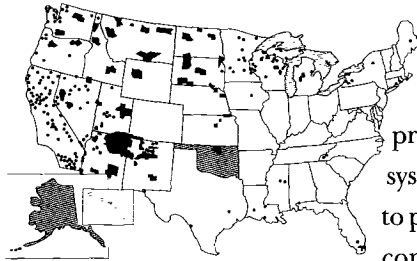
A model program would allocate funds for parent networks, especially among minority groups; involve local media, churches, and other community organizations, including police, to disseminate information; involve greater parent participation; reduce paperwork for applicants; ensure that programs and services are better coordinated; and respond to information requests in a timely manner. Examples of model programs cited by these delegates include the Murphy School District in Phoenix, Arizona; California's Healthy Start Support Services for Children; Even Start in Blackfoot, Idaho; the Maternal and Child Health Program, Handicapped Children's Resource Center, and Referral for Services in the Mariana Islands; and the Washoe Pregnancy Center in Reno, Nevada.

HEALTHY CHILDREN - Ready to Learn



NATIVE AMERICAN FAMILIES

The highlighted States or areas within States are those that contain reservations or a large population of Native Americans. More than 60 percent of Native Americans live off the reservation in both urban and rural areas.



Native American delegates identified the search for information as their overriding issue. Parents with special needs children feel particularly at a loss, and there are too few programs for newborns. Social service systems in Oklahoma and Montana fail to provide Native American parents with comprehensive information on available services, and transportation to health care centers is a serious problem in isolated areas. Supplemental foods are also hard to obtain in these areas. Non-Native American doctors and dentists often refuse to provide services to Native Americans and those who do serve Native Americans are concerned primarily with paying off scholarships and show little compassion toward or understanding of their patients. Housing, especially housing provided by the Department of Housing and Urban Development, is often inferior.

These problems result in and are compounded by problems such as a high rate of substance abuse among mothers, including paint and glue sniffing, which often is undiagnosed. Teenage pregnancy rates are also high, and Indian parents seem to have difficulty communicating about sex with their youngsters. The community's lack of compassion for these young mothers lowers their self-esteem. Furthermore, they often don't realize the need for prenatal care and don't know how to adequately care for their babies.

Native American Families Recommendations at a Glance

Awareness and Entry

- ★ Provide comprehensive information on available services
- ★ Address transportation problems
- ★ Make obtaining supplemental foods easier in isolated areas
- ★ Increase the number of doctors and dentists who serve Native Americans
- ★ Improve housing provided by the Department of Housing and Urban Development
- ★ Improve the detection of substance abuse among mothers
- ★ Provide sex education for teenagers and increase the number of mothers receiving prenatal care

Participation

- ★ Increase funding for programs
- ★ Target funds for programs specifically for Native American children
- ★ Improve cultural sensitivity
- ★ Address communication problems

Transitions

- ★ Protect confidentiality while instituting a national database for social services
- ★ Recognize the status of tribes as separate nations
- ★ View parents as educators of cultural heritage

As a result, many Indians begin life at risk and remain so all their lives.

Native Americans feel that funds to combat these problems are allocated on the basis of head counts alone and that services are uneven and often discriminating. More funding was a universal recommendation. The Native American delegates added that some funds need to be clearly targeted for Indian children so that all their children's needs can be met, regardless of family income or tribal programs. As the 1990 census indicates, more than 60 percent of Indians live off the reservations in both urban and rural areas. In urban areas, the Indian community is culturally diverse, sometimes representing several tribes and languages. Providers need to be aware of this cultural diversity, and services should be provided in these urban areas. One delegate told about being denied special health services because a provider insisted that she use the reservation hospital, which did not offer everything her condition required. Another delegate told of a person who had facial characteristics of an Indian but did not have a tribal heritage; nevertheless, he was sent to the reservation for services.

Indian delegates reminded their white and African-American colleagues that, as Native American parents participate in programs, acting assertively to confront the system and demand that it become responsive defies tribal heritage and culture. Native American parents will not be assertive merely because someone tells them that they must. However, this problem can be resolved if Native American parents accept the role of teachers for practitioners who don't understand tribal customs and history. It is imperative that service providers be taught that it is contrary to tribal culture for a person to look directly into another's eyes when he or she speaks because social service providers have been known to doubt a person's honesty because he or she did not maintain eye contact with the practitioner and deny benefits. Other unique communication barriers include the loss of information or misunderstanding during translation, especially when all words in tribal languages do not have an English equivalent, or vice versa. Programs and the materials they use need

to be tied to cultural relevancy both for children and parents.

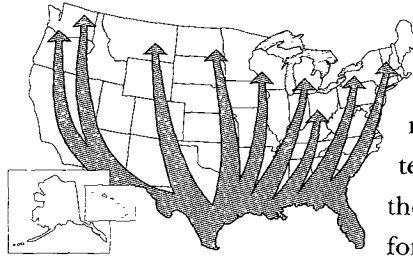
Although confidentiality in health and social service programs is a concern for all parents, it is particularly important for Native Americans. Confidentiality is sometimes threatened when the programs are administered by the tribe because the providers and recipients of services are often acquainted or even related. Holding tribal staff accountable is very difficult. Nevertheless, these delegates, like their colleagues in all the other regions, said a national database network for social services is needed; however, they advised that regulations ensure confidentiality among all services and programs.

In another area, services and programs must recognize the distinct status of tribes as separate nations. The delegates said that professionals need to be aware of and address issues of racism, and the system needs to begin to see Indian parents as prime educators, especially educators of cultural heritage. Practitioners and professionals tend to show little respect for the use of elders for teaching tribal nations, they added.

Head Start and WIC are considered model Federal programs. Newer programs that seem to be working well include Wisconsin Indian Network Genetic Services (WINGS) (in Wisconsin and Oklahoma), which identifies special needs children and helps coordinate services for them; the Trails program, an Outward Bound program; National Indian Youth Leadership, a New Mexico model for youth leadership and mentoring; and Indian Child Welfare programs, aimed at keeping Indian foster care and adopted children in Indian families. The HomeBound and Babies Having Babies programs in Oneida, Wisconsin, both serve teenage mothers. Oklahoma has excellent referral centers in the Tulsa Indian Health Care Resource Center and the Oklahoma City Indian Health Clinic. The Pawnee Benefits Program issues benefit cards that can be used for care by a private physician.

MIGRANT FAMILIES

The arrows on the map indicate the general routes followed by Migrant families as they travel to work during the growing season and harvest of America's crops.



Migrant families also have their own special set of issues of concern, with housing, salaries, health insurance, and injured workers benefits taking the lead. Migrants often must rely on crew leaders who recruit teams of workers and then may exploit them, denying them basic rights (such as forcing them to work on Sunday when they want to attend church) and charging them for free services (such as housing provided by the farm owners). Migrants were largely overlooked in the 1990 census, and the low level of available health care and social services reflects this deficit. The lack of coordination between programs from State to State affects Migrants particularly: They cannot qualify for WIC, Food Stamps, or Medicaid benefits in one State without canceling their benefits in another. If they return to a State, they have to reapply. Migrant parents need some kind of

resource material, available *before* they move, that would provide them with a State's regulations and policies. Federal programs also should be coordinated with the needs of Migrants in mind. For example, the U.S. Departments of Health and Human Services, Agriculture, and Education each define a "migrant" differently, which leads to confusion and causes denial of benefits. Support groups for Migrant families sorely need funding.

Migrant workers who do participate in programs find that they often must travel long distances to obtain services and miss

Migrant Families

Recommendations at a Glance

Awareness and Entry

- ★ Improve housing conditions, salaries, access to health insurance, and injured workers benefits
- ★ Provide controls over mistreatment by crew leaders
- ★ Increase available health care and social services
- ★ Increase coordination of services among State and Federal agencies
- ★ Provide resource materials on each State's programs
- ★ Provide funding for support groups

Participation

- ★ Provide conveniently located facilities
- ★ Address transportation problems
- ★ Examine policies and implementation of food stamp allocation
- ★ Make Food Stamps available for distribution through the post office
- ★ Address communication problems by providing more bilingual staff
- ★ Enforce child labor laws and keep children in school
- ★ Provide daycare services

Transitions

- ★ Provide improved access to programs and other mechanisms to help migrant families prepare for transition
- ★ Make transfer of school credits uniform among States
- ★ Improve sensitivity to migrant families' problems and show respect
- ★ Hold a followup conference.

whole days of work. Transportation is often hard to obtain. Crew leaders often do not allow parents time off to attend meetings. Migrants are often subjected to illegal treatment regarding Food Stamps allocation. One delegate recommended that Food Stamp distribution be alphabetized for pickup at post offices, so that recipients do not have to spend hours waiting in line. Communication is often a problem for Migrants because service providers lack enough bilingual staff or have no one who can speak the client's language.

Keeping Migrant children in school is a pressing issue. Child labor laws are not enforced; children as young as 10 or 11 years are hired to work in the fields. Parents often have no recourse but to have their children work; their family's livelihood depends on their harvesting as much as possible, and each pair of hands adds to their production. This problem is compounded by the lack of daycare for Migrant families. The result is that small children are brought to the fields along side working mothers, or they are left in the care of children who are too young to work, and who are not much older than their charges.

Migrant families, their conference representatives pointed out, face transitions that are almost always double-edged; they are geographic as well as developmental. Migrant families are constantly making transitions and that means new rules and new environments for their children without any mechanisms to prepare for the adjustment. This continuous movement means continually losing friends and family support.

This delegation commented that it is particularly important for their parents to be guardians of children's records. It is common for Migrant families to complete and file all the paperwork necessary to receive public assistance, only to have the growing season change and force a move to another State before the assistance starts. When they get to the new State, they added, the paperwork has to be redone. But guarding the records does not always guarantee that they will be transferred easily or correctly. These delegates said school credits do not transfer from State to State very easily or uniformly, especially when students enroll in a new school in the middle of a term. Migrant parents recommended

that the U.S. Department of Education devise a system that allows classes and credits to transfer from other States. These delegates also called for improved access to routine programs as away to make transitions smooth. They said that bad health conditions and no daycare, after-school care, or social services are the norm for communities where Migrant workers live. They urged that employers of Migrant workers be closely monitored regarding their employment practices, facilities, and use of pesticides.

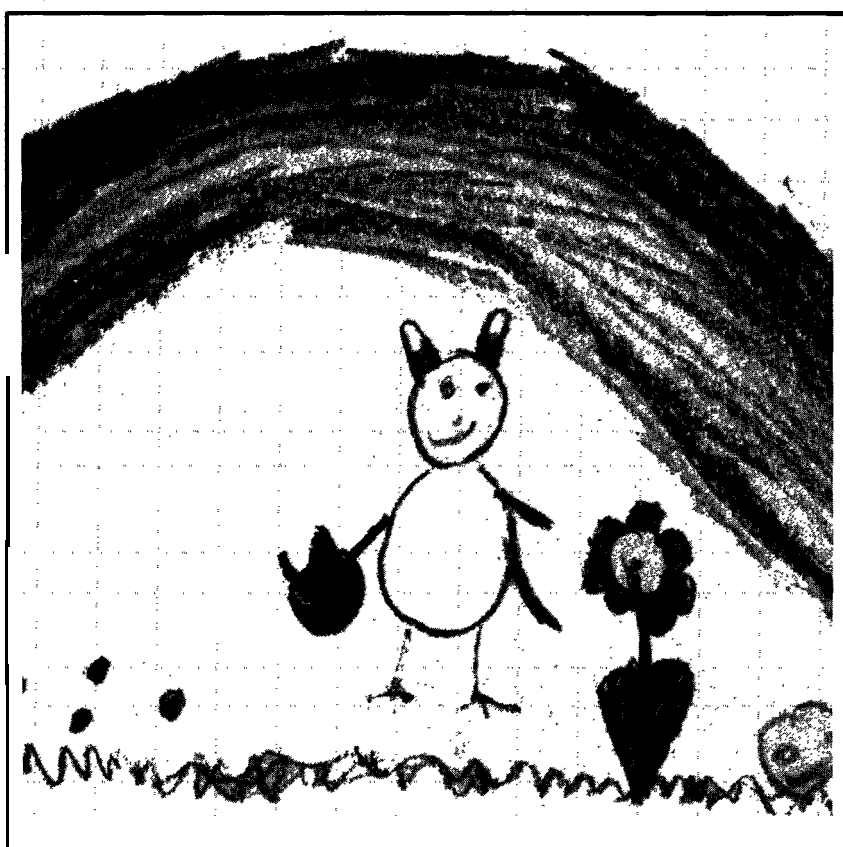
For Migrant parents, developing children's self-esteem often entails demanding respect for Migrant families in general from teachers and other caregivers or service providers. They complimented the conference cosponsors for including Migrant issues on the agenda, saying that more of these opportunities are needed. They urged the continued participation of Migrant families so that they can be partners in raising healthy children ready to learn.

The families agreed that a model program should include classes in prenatal care, dental care, and English as a second language; make Head Start available for all Migrant children; involve parents in policy decisions; bring mobile health clinics to rural areas; fund senior centers for care for the elderly; and sensitize social service staffers to the special needs and cultural differences of Migrant workers. Migrant families are subjected to exceptional stresses and strains, and model programs should take care to address the needs of the family as a whole, to help maintain family integrity.

Among existing model programs, Washington State has a Migrant Council that works with the whole family; the East Coast Migrant Head Start provides continuity of services; and overall, Head Start is an effective program because it is designed to serve the family as a unit.

Chapter 4

Presentation of Findings



Chapter 4

Presentation of Findings

O n the final day of the Conference, the more than 700 participants came together to hear the findings of the Parent Work Groups. The findings were presented by three parent representatives, one for each of the topics discussed: awareness of and entry into health, education, and social service systems; participation in the systems; and transitions from one program to another-within the systems. The parents prepared their presentations of the findings by working with the work group facilitators, recorders, and rapporteurs to determine a national consensus based upon the thorough written notes of the work group sessions. After the parent representatives presented the findings, the issues they raised were addressed by the Responder **Panel**, composed of directors of key Government agencies that provide services to families. This dual panel composed of the Parent Representatives and the Responder Panel was moderated by **Rear Admiral** Julia Plotnick, Chief Nurse of the U.S. Public Health Service.

Parent Representatives¹

Awareness of and Entry into Health, Education, and Social Service Systems

Sherlita Reeves

Parent Delegate from Arkansas

Hi. She [Rear Admiral Plotnick] told you I'm from Clinton country. I live in a very rural part of Arkansas, and so that's the background I come from. I have two children. I have a 14-year-old who is normal, healthy, and looks like she's 18, and an 8-year-old who has spina bifida, a neuralgenic bladder, severely dislocated hips, club feet, hydrocephalus, and growth hormone deficiency and who must take injections daily.



I'm a multidegreed individual, and I think I'm well educated, but I have to tell you that *nothing* in my life prepared me for being the parent of a special needs child. But then, nothing prepared me for being the parent of a teenager, either. So, you know, you just have to learn as you go.

My 8-year-old daughter, who has spina bifida, has been involved in programs like Head Start, which was a blessing to my family. Presently she is on TEFRA,² which, as many of you may know, is the Katie Beckett waiver, and, again, that's been a Godsend to my family.

It can be very frustrating when you are working and trying to do good for your family, and just because

¹The remarks of the Parent Representatives have been edited for clarity.

²The Tax Equity and Fiscal Responsibility Act (TEFRA), Public Law 97-248, enacted in 1982, allows States to amend their State Medicaid plans so that children with special health care needs under age 19 can receive benefits while living at home even though SSI rules require institutionalization under the eligibility criteria. Individual Katie Beckett waivers provide the same entitlements but were granted on a case-by-case basis, whereas TEFRA covers all children in the State who meet other eligibility criteria. Katie Beckett waivers were created in 1982 and phased out in 1984.

you are working and trying to do good, you don't have any more of an idea where to go for services than people who aren't working and well educated. I mean, just because you have a college degree, doesn't give you any great insight into how to deal with children. That's just something we all have to learn.

It's my task today to summarize to you the reports from the groups on awareness and entry, and I wish to let you know that I am speaking to you in a collaborative voice, and not as a single individual.

The Parents' Roles and Responsibilities

The groups felt that the parents should first become informed about their own children's needs, and that they need to be informed about what services are available. It's very important to remember that knowledge is power. And we need to know what our rights as parents are.

Parents should be their children's advocates, and in order to do this, they must first have a belief in themselves. They've got to be able to meet their own needs in order to be equal partners with professionals and service providers. Parents should network with other parents because there is great strength in numbers, but we have to keep in mind that networking can be just one person with another person.

Issues of Concern

There's just too much red tape and paperwork in systems that are not people oriented. It's very difficult to get into the systems, and once you get in, you don't want to stay. An example of this is problems with the Medicaid program. Medicaid says that they will pay for services for children who are indicated by screenings, but they are unwilling to pay providers enough money to make it worth their while. And the end result is the same: the child still gets no services.

The system is not set up to meet the needs of people whose first language is not English and who have a different culture. Their hours are inflexible for working people. If you've got a 9-to-5 job, a lot of times you can't take off work to get your child's immunizations without endangering your own job. That's a

problem. There are barriers for physically impaired people. There's a lack of transportation to providers, especially in remote rural areas. There is no accountability in the system, and if you have a problem, there is often no one to whom you can complain.

Our system fosters dependency. Generations are growing up on a welfare system, and it's becoming the only way of life that they know. In some cases, single parents making minimum wage cannot afford private health insurance to cover their children. And thus, in many cases, it's easier to be dependent on the system than it is to get a job. Welfare programs, such as AFDC, cause families problems; families are unable to get assistance a lot of times unless the father is willing to leave the home, thus breaking up the family.

There aren't enough tax dollars to go around. There aren't enough dollars to go around. Community programs are forced to compete for the same funds. This situation breaks up the community.

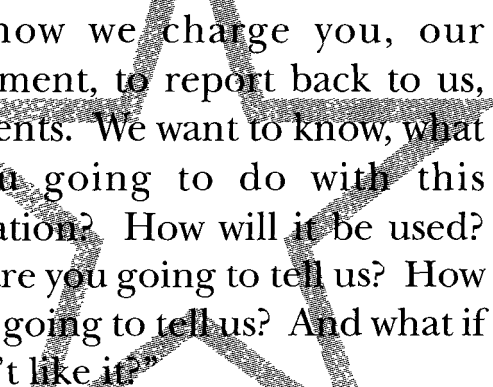
Solutions

Now we get down to the meat of the problem, the reason we came. We feel that there should be school programs, starting in kindergarten and going through 12th grade, that develop social competencies, to prepare children on how to be effective parents and advocates for their own children later on in life. They could learn self-esteem, self-confidence, problemsolving, decisionmaking, and how to get along with others.

We need to build support networks within the community-whatever that community may be for you, if it's your neighborhood, your workplace, etc. It may be people who have similar health concerns, or it might be your tribe.

There should be directories of resources available, locally, statewide, and nationally, with toll-free numbers for resource information. And there should be one-stop shopping for all mandated programs, such as Medicaid, WIC, or Food Stamps. And this should begin with a single application form, or as some people say, a "universal form."

Children need a comprehensive health care system from the time they are born. We need to provide



“And now we charge you, our Government, to report back to us, the parents. We want to know, what are you going to do with this information? How will it be used? When are you going to tell us? How are you going to tell us? And what if we don’t like it?”

prenatal care for everyone. We need early intervention. Public Law 99-457 is aimed at children 0 to 2 years of age. We need to target new parents. We need Head Start for children ages 3 to 5. Those are just some of the programs we felt had worked.

Parents should have a way of talking back to the system. Parents need a common ground with agencies, a respectful partnership that recognizes each other’s needs. This relationship is going to foster and encourage easy entry into the system. Parents need to build a method to evaluate the services they receive and hold service agencies accountable for the quality. There should be persons designated to respond to all complaints in a timely manner.

Children are our greatest natural resource and our future. There should be an all-out media campaign just as intense as the one for anti-smoking and AIDS awareness. It speaks very poorly of our country that we had laws to protect animals before we had laws to protect children.

We need to define our national health care system. This country needs to make up its mind. Is health care a right, or is it a privilege? Is insurance a right, or is that a privilege? There’s a parent here at this conference

today who is paying insurance premiums of \$1,000 a month. *How?* That’s \$12,000 dollars a year! How many families can afford that?

In closing, we’ve been asked to report to you, our Government, on everything that we’ve done in the last few days. And now we charge you, our Government, to report back to us, the parents. We want to know, what are you going to do with this information? How will it be used? When are you going to tell us? How are you going to tell us? And what if we don’t like it?

Participation in Health, Education, and Social Service Systems

Ellie Valdez-Honeyman

Parent Delegate from Colorado

I’m from Region 8 and the beautiful and mountain state of Colorado. I was born in the southern part of the state in a place called El Valle San Luis. It was there that I learned to speak Spanish with my grandparents, who were very special to me.

My husband, Mike, and I have six children. They range in age from 21 years-and I know I don’t look that old, but I am-down to 20 months old. We have three girls and three boys, and three of our children have disabilities. Currently, our home is also blessed with the presence of two grandparents, who are there for an extended stay. Two of our children with special needs are attending their home schools with support from special education. Our 5-year-old and our 20-month-old attend an integrated daycare program at a wonderful place in Denver, which has been our family’s Point of Light, called Laraden. There, our daughter Jamie, who’s 20 months old, also receives her therapeutic intervention.

We’re a complicated family, and we have some fairly complicated needs. We’ve had to challenge the system at all levels to get what we needed for our children. But right now I’m not here for them, and I’m not here for myself, or for my State, but I’m here to speak for parents all across our country who are represented by all of us at this conference. Every work group

addressed the areas of awareness, participation, and transition. And I'm going to try to speak about our collective thoughts on participation. I took the liberty and came up with a definition that I hope says what you thought participation means. Participation is being an integral and meaningful part of whatever it is that we need to be healthy families ready to live and learn.

In participating as families, we all identified some responsibilities and roles that we have. We need to provide for the needs of our children. That means giving them those things that can be seen and touched, like food, clothing, safety, health care, and quality time, which will in turn manifest itself in good self-esteem, confidence, or as one mom from the southeast said, [so] "They'll be emotionally and socially straight." After those immediate needs are met, we need to instill in them a spirituality that encourages values, morals, and respect for themselves and for others.

We need to be advocates. We need to be advocates for our children. We must get their needs met first, and after we do that, we can become advocates for other Families who are just starting out, or who are stuck. And finally, we can advocate for the system components that

work for us. We need to develop partnerships with systems. We must become partners with the systems, and becoming partners means there's an equal status and respect of input, as well as capability.

Parent to parent—that can mean a lot of things. But, parents, I suggest that we need each other. No matter whether we're a stepparent, foster parent, single parent, birth parent, adoptive parent, grandparent—we need each other. And we can help each other by supporting, mentoring, role modeling, or whatever it is that links us together. We need each other.

We're responsible for community education. We must become involved in our communities, because by our presence, we'll educate about the benefits of integration and inclusion and we'll get beyond just cultural awareness and cultural sensitivity. We'll all become culturally competent. In other words, we won't just serve tortillas and peanut butter around Cinco de Mayo, but we'll have all our forms available in the languages that the people speak. We'll understand that when a Native American mom doesn't make eye contact, it's out of respect, not disrespect. We can go on and on about those areas of competency and what that means.

Regarding these parents' roles, we identified some issues of concern. There were many, but the ones that came through loud and clear were the stigma of receiving services, the stigma around being poor, a circumstance over which babies have no control. One of us here identified "a national psychology" that stigmatizes you if you are a recipient of certain Government benefits. One mom described her embarrassment at the checkout when she overheard someone make a comment about her purchase of cookies with her Food Stamps. She was almost in tears when she said, "Doesn't every child deserve a cookie now and then?"

Ironically, we have families who can't get those benefits, because they make a few dollars over the maximum. A parent from New Hampshire says she can't afford to get a job, because she'll lose income and her health care. Eligibility is the barrier. Eligibility for services should not be just income-based. We can't forget those families who should be eligible because they have children with overwhelming needs.



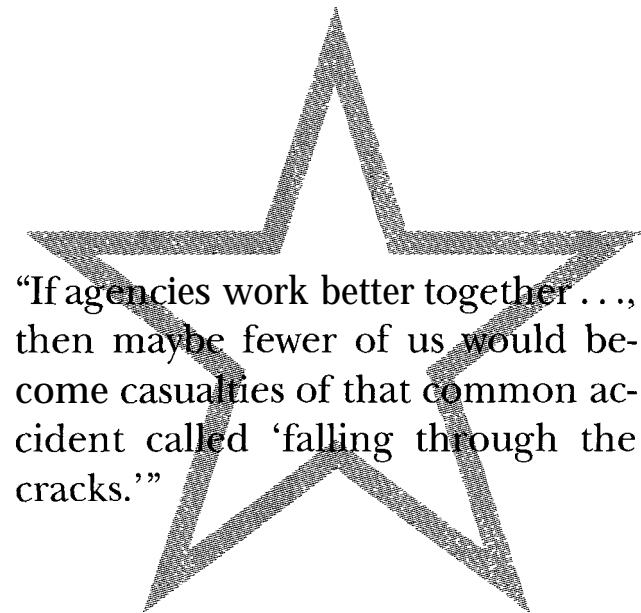
There were lots of barriers to participation in services, programs, and support. But some of the ones that kept getting mentioned were language, and not just non-English, but language full of complexity and jargon. “System language” that only a bureaucrat can understand, and that *they* sometimes can’t even translate, is also a barrier.

Transportation is a barrier in rural areas. There aren’t enough services, and sometimes you have to travel far to get what you need. In large urban areas, lack of public transportation can keep you away too.

Inflexibility is also a barrier. We need flexibility from our employers to get to the services. We need services to be available at flexible hours and in flexible places. Families need to be able to identify who their community and family are. A big barrier sometimes develops when the systems try to define family and community.

Bureaucracy is complexity, and often the bureaucrats don’t understand the system. Paperwork is complicated. One mom in the northeast told us how she was eligible for Medicaid and she had her card, but she couldn’t find a doctor who would see her. Doctors are often leery of Medicaid patients, not just because of the low reimbursement rate, but because of the paperwork and the time involved in getting their money.

Being the proactive and sensible people that we parents are, we identified some solutions, and we put them into two categories. The first one was local initiatives. We identified that we need flexibility in service delivery. A variety of hours and days when the services are available would really help us. Our providers need flex time, if necessary. Our moms and dads who work need support after 5:00 p.m. and sometimes on weekends. We need consistency in funding. We want to be sure that the services that we need will be there tomorrow. Locally based services and support need to be available and close to home. We want our children with disabilities to go to school with their brothers and sisters and neighbors. We want all children to get a fair shot at education, not based on the income-or lack of it-of their parents. We have to foster self-esteem. The services, supports, and benefits



“If agencies work better together . . . , then maybe fewer of us would become casualties of that common accident called ‘falling through the cracks.’”

should be viewed in ways that are meant to help families to become enabled and in which empowerment is facilitated. We all have the potential for empowerment. More support should go to programs that make families rejoice in the success of being self-sufficient.

As parents, we accept some responsibility. We think that all parents have to be involved, as budget planners, policymakers, and partners in decisionmaking. We saw interagency collaboration as a key solution. Good services will result from good interagency collaboration, and once again, the collaboration should include parents-not as tokens but as real participants, who are respected and maybe even paid for their expertise. If agencies work better together (or, as a bureaucrat friend of mine from Denver said, “smarter, not harder”), then maybe fewer of us would become casualties of that common accident called “falling through the cracks.”

The second category is Federal initiatives. Our comparieros in Region 2 actually put together an initiative for a partnership across all Federal agencies that would include families and agencies from local levels. This partnership would be a formal structure that would create a standard in which service systems welcome and embrace families and use proven models that work, such as Head Start. The principles outlined in the plan would be embodied in the design, delivery,

and evaluation of services. The philosophy must include family-centered, comprehensive, and accountable service and support. And again parents must be included as equal partners.

Dr. Novello, you issued us a challenge when we came here, and you've already heard one challenge. We're issuing another one. We as parents voted last night, and we decided that, from Washington, you should lead that initiative.

I want to thank Rosa Palacious, a parent who supported me last night through the long process of putting all these collective thoughts together, and I just want to share with you something that I learned at this conference. I saw, and I see, areal **beauty** in the diversity here, and we need to celebrate in that diversity. I also felt a power in collectiveness, and I think we need to harness this collective power. We need to identify those areas that are important to all of us, such as family, health care, and education, and we need to unite as parents-all kinds of parents-to make our families healthier and happier, to make health care accessible, and to make education more than just an academic experience, but an experience in living. To do this I suggest the leadership must come from all of us.

Transitions Through Health, Education, and Social Service Systems

Larry Bell

Parent Delegate from Delaware

Being up here makes me pretty nervous, especially in following these very competent young ladies who went before me. I want to take this time to thank Dr. Novello, and all the parents that were here, and all those people that kept me up all night last night trying to put this together. And especially for the parents that were in Region 3, which is the group that I was in, for their support. It is an honor to have been chosen to stand and represent you.

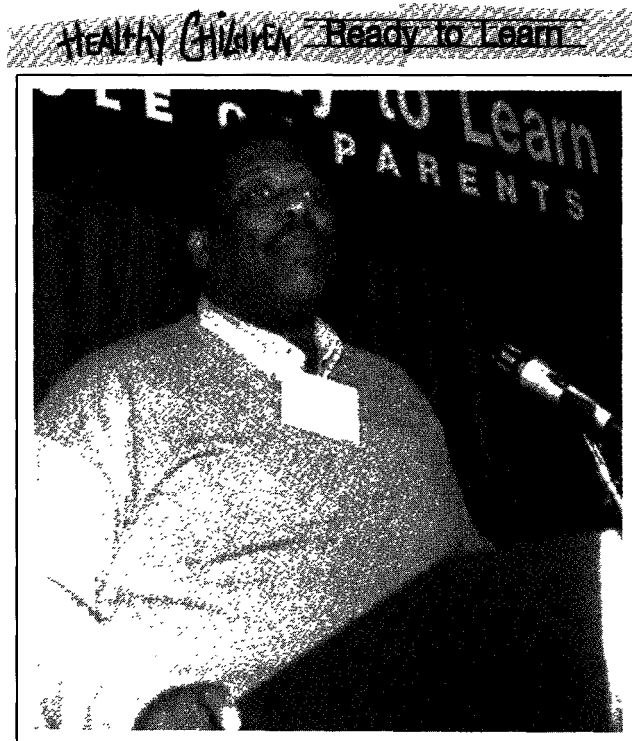
I was waiting, and I saw my wife come in-are you here, somewhere? Yes, okay, I feel better now. They were calling me this morning wondering where I was, and I

came down, and I had all these people (I guess security people) with walkie-talkies calling and yelling, "They're coming through." It made me feel good as an African-American male to have all that security and not be on my way to jail.

My name is Larry Bell, and I'm from Delaware. I have five children and three grandchildren. I'm a second-generation Head Start parent. I was involved with Head Start when my children were in Head Start, and now I have custody of one of my grandchildren who's involved in Head Start, and that's how I ended up being involved in this process today.

The purpose of my presentation is to bring together all of the work that the parents have put in so diligently over these past 3 days and talk about issues of awareness, participation, and transition. And my topic is going to be transition.

First, I want to share a little story. I heard a minister friend of mine-and by the way, I forgot to tell people that I was a minister and was going to be passing the collection plate in a few minutes-I heard a minister friend tell a story of how every time he went home and they sat down to dinner, they always had squash. He hates squash. Every



time they passed the food around, when it came to him, he would pass it on to the next person, and his mother would say, "Boy, what's wrong with you? You know you don't pass food without taking some and putting on it your plate!" He would say, "But Mom, I hate squash!" She would take the squash and proceed to put more on his plate than he would have if he had done it himself. He would say, "But Mom, why are you making me eat this? I hate squash." (And he's a grown man.) And his mother would reply, "Because it's good for you." The point is this: the information that we as parents are presenting to you, especially the legislators, is the truth. Some of that truth that you hear will be "squash truth." It will be truth that you may not like to hear; it may not feel good, but it will be good for you. And throughout my topic here, we'll be covering the issues and roles and responsibilities of parents; we'll be dealing with the problems, issues, and concerns as well as solutions. And I kind of combined them together.

The thing that I want to leave and impress on all of us before we leave here is that all of us have a responsibility when this Conference is over. People are asking, "What's going to happen with the information? Is this just to be another time that we come together and share information and nothing happens with it?" It might be, but knowing from what I've seen, the time that I spent with and around Dr. Novello, I don't believe that's going to be the case.

But all of us, when it comes to working with problems, solutions, and transitions, have a responsibility when we leave here to go back to our communities and meet with various agency officials to begin to talk, share ideas, and discuss the roles of parents and the roles of people involved in the system. We all have a responsibility when it comes to the transition of our children. Our charge to our parent delegates is to go back to your communities and meet with the officials of whatever system or systems that affect or impact on your children. Sit down and define those roles.

When we talked about transition, we came up with nine major issues. And the first one is that parents need to participate in the transitional process. Parents need to be aware of their children's needs, including health

needs and special equipment needs. They should be encouraged to articulate those needs to the systems in which they will be involved. Parents need to be prepared for and about the transitional process. But we need to remember that transition really begins with the transition of the parent, to prepare children for the transition-to do things like introducing them to new people, taking them on a tour of the school, finding out the daily **routine**, and talking to our children about that process. To prepare our children for transitions such as having their parents at these conferences that involve their children, people need to talk with their kids about the change as soon as they know that it's going to happen.

We also decided that it would be very helpful to develop a resource manual, information that would be available and accessible to the parents so that, when they move through different systems, they would have a source with the names and numbers and contact people. Then, when other needs arise in the future, they will have something in their hands so that they can contact somebody to have those needs addressed.

We felt that parents also should be encouraged to be good recordkeepers, to have copies of all their children's records so that as they move through the transitions, if the system fails to make sure that information gets moved on or passed on to the next system, the parents at least have a copy of that information to make sure that it gets passed on.

We thought that parents needed to demand respect for themselves and for their children and that the systems that they're involved in need to respect them and recognize that parents are professionals too. We felt that one of the other things that would help in the transitional process is for the systems and the parents to sit down together and share and clarify their roles in who's going to be responsible for what.

We also need to improve communication between systems. Improving communications would make for smoother transitions; it would help decrease turf wars, avoid duplication of services, and help to promote the continuity of services.

We felt that program materials need to be written in the language of the parents, to take into consideration

the languages of non-English-speaking people. **Also,** we suggest using picture books for those parents who might be illiterate and being sensitive to language that doesn't always translate exactly into English. Many of the Native American terms don't always compare when they are translated, and we need to be sensitive to those kinds of things.

Successful transition depends on having everyone involved to learn to trust each other and the systems that impact upon their lives and the lives of their children. We want you to know that this takes work on both parts to develop that kind of trust. We want a system that we're involved with to avoid technical jargon and using terms that we don't understand. When you sit down to work with parents to develop an IEP, make sure that you speak in terms that the parents understand, and make sure that the parents are aware that they don't have to sign an IEP if they disagree with it.

Another area of concern was that programs and staff must be culturally sensitive and relevant. Systems need to see parents as the prime educators of their

children and especially educators of their own cultural heritage. Programs need to be aware of and address issues of racism that occur during transition-or any time that it surfaces directly or indirectly. Remember that the sensitivity in this area goes beyond just ethnicity, but also should take into account social and financial status and spirituality issues. Remember to label cans, and not kids.

Also, we must focus and work on developing parental and child self-esteem. We want to focus on the children, but when you're working with the children, remember that parents need self-esteem too, and those issues need to be addressed. Parents must be good role models for their children and be good role models throughout the transitional process. Sometimes this means finding a good role model for the parent.

One of the responsibilities of parents is to love their children, but we know that before you can love other people you first have to love yourself. Parents must learn to be able to feel good about themselves before they can help their children feel good about



themselves. We want to make sure that children know that their feelings about the transitional process are important and that they should be encouraged to share or to express those feelings. We should make an attempt to bolster childrens' self-esteem so that they won't be afraid to speak up. At the same time, we should bolster parents' self-esteem so they won't be afraid to speak up, so that they won't be afraid of the systems that impact upon them and will be able to confront the system. Some of the parents said that other parents won't speak up for fear that if they do, they may get involved in a system that may end up investigating them or even make an attempt to take their children. Because of those kinds of fears, sometimes they are uncomfortable confronting the system. But we need to encourage parents to stand up and be the primary advocates for their children.

Another concern was that parental involvement must be consistent across systems. Many times parents who are involved in the Head Start program are constantly involved in the progress of their children; they volunteer in the classroom, they spend time with them, etc. Then, when they move or enter other systems or the school system, they're not that involved. We feel that we need to keep the parents involved and keep that involvement as they make transitions throughout the systems so that our children can be healthy and ready to learn.

We also felt that parents should be involved in program design and the policymaking decisions that affect and impact upon their children. One suggestion is that we form parent boards, which are very prevalent in Head Start but do not exist in many other systems. After the transition occurs, parents need to continue to be involved. For example, parents that are involved in Head Start need to stay involved as their children grow and move through other programs.

Parents need to form their own support groups. When they do, programs should work with them. In other words, when a parent group forms a support group to help themselves and to help other parents work through the transitional process, the programs and systems should be there for them, to support them,

help them learn the transitional process, and provide materials or whatever they need to make that transition as smooth as possible.

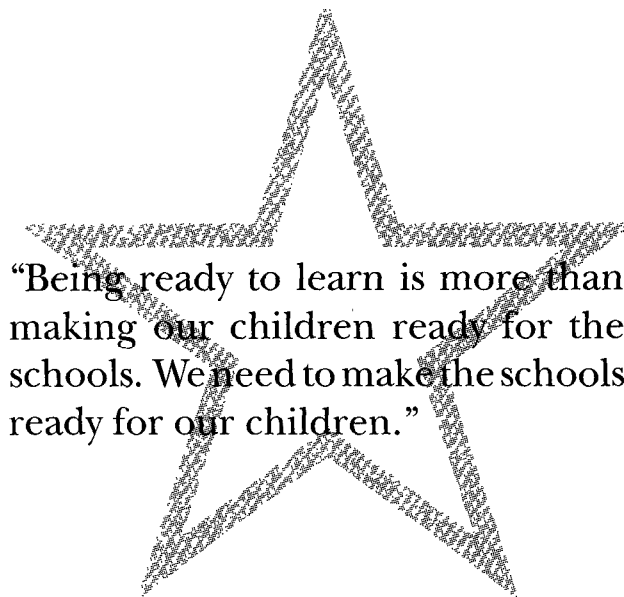
Program counselors should be appointed to help parents prepare for the transition. Also, parents need to be aware of not only the needs of their own children, but the needs of others-to move away from, "me, my four, and no more."

Consistency is the key to successful transitions. We need to be aware of the impact on children and parents of abolishing programs without notice, and many times without preparation to have those needs met through another area. We need stabilized funding so that programs can address the problems, instead of just looking at the symptoms.

Someone suggested that the transitional process would be easier if we developed an interstate communication system. We should create a national computer network so that the information on parents in one State could be readily accessible to another State. When people such as the Migrant workers move from one State to another and they have to apply for benefits, they have to close out their file in the first State, reapply at the next, go through that whole process again, and reopen their files. Often it takes a long time before they get the benefits. Sometimes they are ready to move on to the next growing season or the next location before the benefits even get started. So, if we had a national network, that information would be readily available, and that could speed up that recertification or reapplication process.

Also, another thing that came up was to create a way that school credits could be acceptable from State to State. People move through different situations. They have things that are credited in one State, and when they go to the next State, the school says, "I'm sorry, but this is not credited here." Then, the child has to go through that whole process again.

Establish one-stop shopping-and I won't elaborate on that because it has already been stated. Decrease the time spent on paperwork. Make forms less complex. And make an effort to cut down on the duplication of information during the recertification process. Many



times parents go in to be recertified, and they give the same information they gave 3 months ago. Sometimes in Delaware, when you go to be recertified or to get services, they tell you that you have to be at the social service agency at 7:30 a.m. They see you at 8:30 a.m. or 9:00 a.m., and then they give you paperwork to fill out that you just filled out the last time. No information has changed, but they say, ‘Well, you have to do it.’ We could cut down on that process and speed it up.

Workers need to be sensitive to the needs of the parents who come in and should be aware of the stereotypes and not have negative attitudes towards them, because they wouldn’t be there if they didn’t need the help.

The other area of concern was flexibility. We need to make the eligibility criteria flexible. For example, some people have incomes above the guidelines to receive Medicaid but also have children with special needs. They can’t get regular insurance because the child has a preexisting condition, so the insurance company does not want to cover them. So those people get lost in the cracks. We need to pave the way of smooth transitions by making programs and facilities flexible.

One of our delegates expressed that she has a special needs child who has been mainstreamed into the classroom. When that child has to go to the

bathroom, he’s made to go to the other side of the school because it takes him a little bit longer to use the bathroom, and they don’t want him to hold up the other children. We don’t think that’s fair, and that situation needs to be addressed.

We already talked about flexible hours. Employers need to understand the parents’ need for daycare, leave for medical visits, and appointments with other programs. Remember that the family and their individual needs still exist when income levels change.

Transportation was an issue and must be improved and addressed, especially in rural areas. Without transportation, the children are not going to be able to make successful transitions between programs and obtain other needed services.

Another area of concern is increasing and promoting the use of school social workers. Social workers could act as advocates for parents and children so that they can help them with the transitional process. They can help families access services and become a primary link between school systems, parents, and the community.

The last and final area is that legislative action must be taken to improve our children’s transitions. First, we see a role of the parent to take the responsibility to elect family advocates in political offices. We need to work to develop Federal and State laws and regulations that better address the families’ needs to make the transitional process much easier. We need to find a way to enforce the laws that are already on the books. We also need not to just address the needs of one individual’s problems. For example, one of the parents shared that they were in the process of suing the school system for some needs for their children and that when that fight is over, and that parent wins, the next parent has to go through the same process. We think that systems need to learn from those fights with parents and those kinds of things that happen. They need to learn from the results so that other parents don’t have to learn how to fight the systems better. We need to make sure that our programs are adequately funded so that the needs that they are designed to address can be addressed.

In summary, we want to remind you of the three C’s. Consistency, continuity, and coordination of

services are necessary to promote healthy children in families that are ready to learn. We want to issue another challenge—and this is not necessarily to Dr. Novello—but we not only want our children to be healthy and ready to learn. Being ready to learn is more than making our children ready for the schools. We need to make the schools ready for our children.

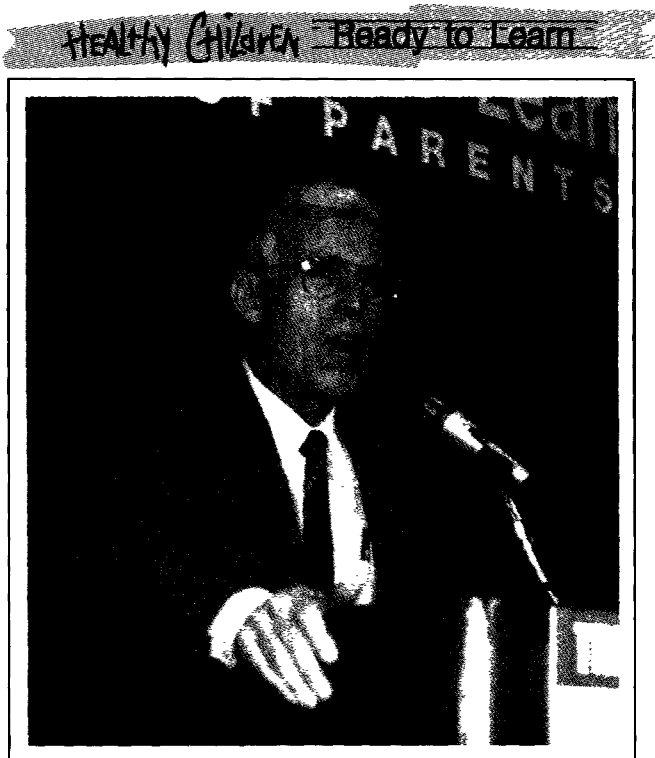
Responder Panel³

James O. Mason, M.D.

*Assistant Secretary for Health
U.S. Department of Health and Human Services*

I want all of you to know how much I appreciate this opportunity to be here with you. I want to express appreciation to all you parents, and I don't need to tell you that your three representatives up here are tremendously articulate and very well prepared. I could talk for 2 hours just in responding to what the three of them have said, and obviously I don't have time to do that. Let me say that I'm not just the head of the U.S. Public Health Service; I'm also a father. I have 7 children and 17 grandchildren, so I could sit out there as well as stand up here. I hope I can express my sympathy for your point of view both as a governmental official and as a parent.

I think it was Ms. Reeves who talked about the importance of our children. So often we read in the newspapers about being competitive with our automobiles, electronics, or pharmaceutical industry, but we are here to reaffirm that the most important product that this Nation has is its children. Our children are the future of America, and every minute we spend here is time more than well spent. I believe—and I don't think it's just because this is an election year—I've never seen a meeting where the President and three departmental heads (three Secretaries) came, and that's a commitment of this Government to the importance of children and doing something in this partnership between the Federal level and parents.



I don't want to repeat what has been said by other speakers, but I want to respond to a number of questions that were raised. When President Bush came here and talked about his comprehensive plan for health care reform, he was addressing a number of the problems that have been described. This reform, which will provide tax credits or certificates and tax deductions, will encompass 9 million Americans. It will provide access to health care services for all poor Americans. It will create insurance pools so that people at high risk will not have to pay those higher premiums; they'll be in the same pool with many other folks, to average the risk out. The President talked to you about health insurance security so if you move from one community to another, or from one job to another, your health benefits would be portable. Then he talked about choice. You see, choice and a tax credit (a certificate) empower a parent; you don't have to be part of a system for just poor people. You take your certificate and you buy your health care from a program that will provide the quality and the content of

³The remarks of the Responder Panel have been edited for clarity.

services that you need. Then he talked about affordability and cost containment. If we can convince Congress to enact this **plan**, it will begin to address some of the health care problems that you are encountering and that I encounter as a grandfather.

I would just like to answer the question: 'What are we going to do?' I just want to mention two things and then I will sit down. First of all, we are here to listen, and I think listening is probably the most important thing you can do so that you understand the concerns. You've heard the recommendations for solving these problems. But we need to do more than listen. Here's one example of what I am going to do. Each quarter I meet with the officials of State and territorial health departments and with your State health department commissioners. Each quarter I meet with the U.S. Conference of City Health Officers and the National Conference of County Health Officers. I'm going to discuss the things that you've been talking about with them because this is a partnership. It was said that leadership should come from all of us and, of course, it's got to come from parents, our neighborhoods and communities, our cities, our counties, our State, and the Federal Government. Only when we all provide that leadership will this system really work optimally, and I will pledge to you my support to do all I can to work not only at the Federal

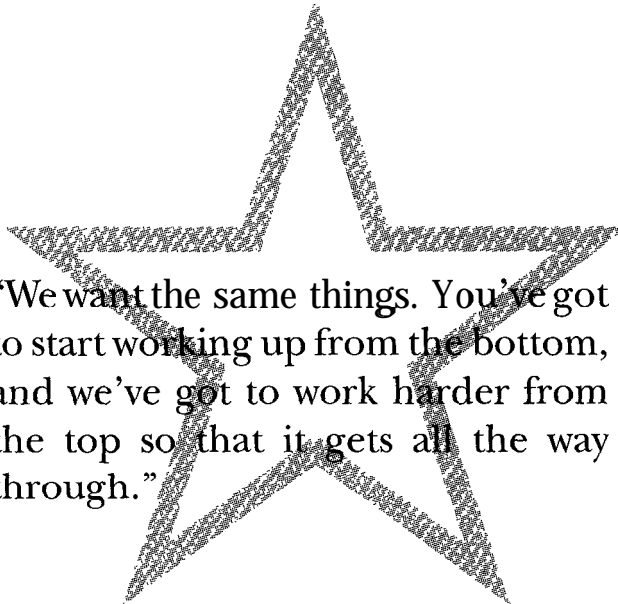
level but down through that system of health officials to see whether we can implement your recommendations.

Now let me give you an example, and time doesn't permit me to give many. I agree with 98 percent of everything you've said. Let's talk about one-stop shopping. You want one-stop shopping, and I want one-stop shopping. Why don't we have one-stop shopping? There are communities-and I have visited them-in the United States of America where they have one-stop shopping. If we all want it, let's do it! There isn't any disagreement. We've talked about having a uniform application form. I'm holding up a little document that's called a Model Application Form, and this was published in the *Federal Register* on December 4, 1991, a little over a month ago. It was developed in collaboration with State and local people, and it involved the Department of Health and Human Services, the Department of Agriculture, and the Department of Education. So, at the Federal level, we want a simplified, unified, uniform application. Now why don't we have it? We want the same things. You've got to start working up from the bottom, and we've got to work harder from the top so that it gets all the way through.

You've talked about flexible hours. You want flexible hours; you not only want them, you need them. And we want flexible hours. Last Friday, Secretary [Louis] Sullivan [Health and Human Services], Surgeon General Novello, CDC Director Bill Roper, and I were in San Diego to talk about an immunization initiative for infants. And what were we pounding the table about? Flexible hours, so that parents could bring their kids in the evening, on weekends.

Let's make the systems user friendly. You want user-friendly systems; we want user-friendly systems. Let's work together to get it. We're not against each other. We're working for the same things, and somehow we have to get it into the middle. And I'm willing to work on that, and I know you will as well. I'm simply trying to say that we are striving for what you want, what you are talking about. Perhaps we can put more power into our grant applications.

Let me just say that we often provide funds for programs that you use, but we don't hire or fire the



"We want the same things. You've got to start working up from the bottom, and we've got to work harder from the top so that it gets all the way through."

people that provide those services. We can talk more, and we will, but we are going to have to work from both ends if we are going to make those services user friendly. We want it, and we'll do all we can; we've heard you. But don't let them kid you down at any other level. We want it; you want it; let's get it. Let's work together.

Let me just end by talking about this document. We have what we call Healthy People 2000. This is not a Federal program; it's a national program. You helped develop the 22 priority areas and the 300 specific, measurable, realistic goals of where this Nation could be by the year 2000. We've pulled Healthy Children 2000 out of a much thicker document, and of the 3,000 measurable objectives for the Nation for year 2000, 170 of them relate to mothers, infants, children, and adolescents. We hope that you will work with us so that **even** before the year 2000, as soon as possible, this Nation will have arrived at where you—as you helped us develop these—said we ought to be. And we're willing to work with you; we are partners, and we thank you for your input.

John T. MacDonald, Ph.D.

*Assistant Secretary for Elementary and Secondary Education
U.S. Department of Education*

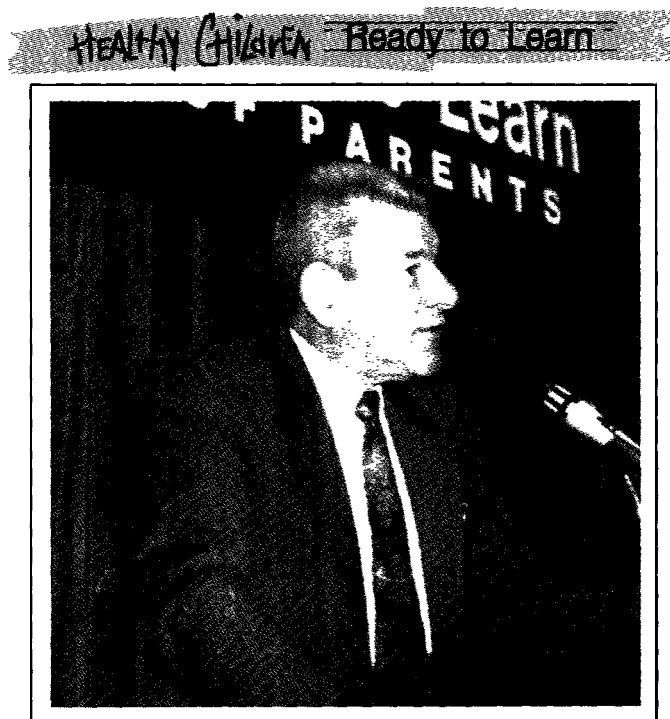
I would like to thank our presenters for what I consider to be an extremely inspirational message, but one that has a great deal of meaning to us. I would like to focus my comments in terms of the presentations on children and their families. I just returned last night from the Organization of American States meeting in Guatemala City on issues that affect the hemisphere in terms of the same kinds of things that we are talking about today—precisely the same kinds of problems that you've brought here. We are dealing with a hemispheric problem that **we have to** address if we are going to survive, not just as a Nation, but as a hemisphere.

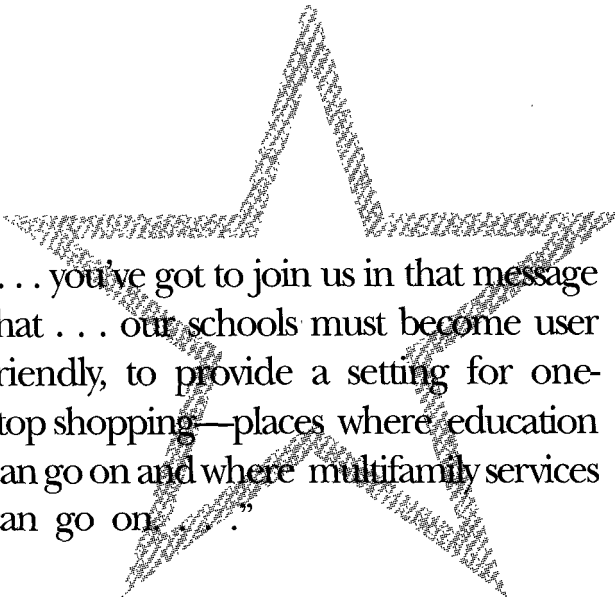
What I heard today, in sum, means involvement, flexibility, a role of advocacy, and finally, as Larry [Bell] shared with us, consistency, continuity, and coordination. I would like to talk a little bit about commitment, as the other C, to children and their families in an integrated way, a much more integrated way than we've ever done before. In my trips around the country and

also in spending 34 years in this business of children and families, I found that, on the awareness issue, it means you must not only be made aware but you must have access.

Jim used the term “user friendly.” Our schools basically have never been user friendly because the schools that we have today are designed for a society, frankly, that doesn't exist today in most areas. I can remember, some months ago, [Secretary of Education] Lamar [Alexander] convened a group of us with an eminent sociologist, a guy I have a lot of respect for and who has done a lot of work in this area for years. We were kicking around the question, “Why don't our schools work any more?” And he said, “Heck, it's very basic. What you are trying to do with your schools is for a bunch of folks who don't exist any more.”

This gets to the access issue, what you need to do with folks. They can't get at you, and you can't get at them. So why don't you think about it? I think back to the experiences I had as a principal years ago, working in an area where poor parents had many of the same problems that you have addressed in your presentations. They worked. They had to work. They had to get their youngsters off early; they couldn't get back to





“... you’ve got to join us in that message that . . . our schools must become user friendly, to provide a setting for one-stop shopping—places where education can go on and where multifamily services can go on . . .”

school to attend sessions or conferences or this, that, or the other thing. At that time, we had Title I—that was 27 years ago, when I came on board—and we developed what we called extended school. This is very similar to what Lamar mentioned that Decatur [Georgia] is doing now. We have the Federal resources to open up the access issue. You can change the mindsets out there if you join us in that attempt, working with our State commissioners, your State legislators, and your local school folks to say that there is a system out there that will support your needs, if it is properly designed. We want access to it, and we want to use it. But you’ve got to join us in that message that we are trying to get across to people that our schools must become user friendly, to provide a setting for one-stop shopping—places where education can go on and where multifamily services can go on in terms of local agency services, State agency services, and, of course, the educational services that should go on on a continuum, places where a school operates from early in the morning until late at night and on weekends and is open during the school year, where it never closes, and it shouldn’t. It’s your largest real property investment. It doesn’t mean the teachers, as Lamar pointed out in his remarks, have to take on all these other chores. They are not trained to

do so-fine. But with that kind of setting, or a setting comparable to it in a community, we can reach and provide for children and their families the kinds of needs that we need to meet today.

It really bothers me terribly—to the point where I don’t understand it—when I think back to the late 1950s and 1960s. When we built elementary schools, we built little clinics in them, and dental centers, and so forth. Try to find a new elementary school today that has that provision where we can provide that kind of service to a child and his family. It doesn’t happen any more. We have to return to some of the things we identified earlier on that parents need and children need and get back to it and make those provisions and open up those schools to do those things.

Let me talk about transition for a minute. Larry [Bell] was talking about transition. Let me throw out a bias of mine that we’ve been trying to work with—[Commissioner of the Administration for Children, Youth and Families, Department of Health and Human Services] Wade Horn and his folks. Transition, to me, means from conception to birth; it means from birth to school and community; and it means to the final thing that the President has also mentioned, and that is to making a life. Unless we have the kind of system in place that provides for that and can deliver that, we’re going to find ourselves generationally not making strides that we need to make to address the needs that we have today. Looking at some of the things that I looked at for the past 3 days in a Third World country—that can’t happen here. We have the ingenuity, resources, intellect, and experience that most people don’t on how to approach this effort, and we can do it.

Let me say in closing that if we use what we know and use it creatively, we can develop support for what we are trying to put through in reauthorization of all the elementary and secondary programs—that’s 57 programs and currently over \$9 billion. What we are trying to say is that we need a massive urban intervention program utilizing Federal resources in conjunction with State and local resources to provide for communities, an opportunity to plan for whatever number of years it takes to pull those resources together, locating the school or another center

as a hub to provide an extended service or extended school concept so that children and their families can utilize the various resources in collaboration to **accommodate** the needs we have.

We have many programs out there currently, for example, that can help each other. For example, Wade's program [Head Start], *even with the* President's increase, will still not serve all the youngsters who are currently eligible. But Wade can use our program Even Start, which *is* for children 0 through 7 years old and their parents, to provide not only parenting and child care services but also job training and placement services. That program can **buy** Head Start services, can be used to expand Head Start services, or can create its own. Our Chapter I program, which is basically age neutral, can also be used to buy Head Start services, expand Head Start services, or buy their own.

In other words, what I am saying is that in terms of integrating what we have currently on the books today, we can do a better job. With our Department of Agriculture, with its Women, Infants, and Children [WIC] programs, we've recently signed a Memorandum of Understanding with them so that our Migrant programs can utilize WIC services. We want to expand that to Even Start because Congress, on our request, has now expanded the age range, not for children from 1 through 7 years old, but from 0 to 7; I wish I could get it from prenatal to 7. But it's in this way that we tie things together, and the Surgeon General and her office with the Healthy Children Ready to Learn Task Force has been instrumental in pulling those of us together who have been working on this so that, again, we are more integrated than we have been before.

We will continue to strive in this direction, but we are going to need your support with Congress to continue in this direction, where we are pulling together and coordinating all the Federal efforts around the one focus-what we need to do for our children and our families who need them the most. Thank you very much.

Catherine Bertini

*Assistant Secretary for Food and Consumer Services
US Department of Agriculture*

President Bush has told those of us whom he appointed to jobs in his administration that he wanted us "to work to reorient government to better serve the needs of individuals." I remember that quote exactly because I thought that was so critical to defining our jobs; it is certainly critical to defining why Dr. Novello has convened this Conference: to talk about one group of people-children and their parents-and how, by working together with parents on behalf of healthy children, we are helping children be ready to learn and to grow strong. Your confidence in Dr. Novello is very well placed, and I know that she has been not only an outstanding spokesperson for these issues, but also, in convening all of us together, is making a constructive effort to seeing this happen. I've learned a lot already today, and I'd like to share some thoughts in several areas: one-stop shopping, service coordination, improving services, empowerment, and then finally some ideas about solutions.

Before I start, though, first of all I want to explain why I am here. As Secretary Madigan said when he spoke yesterday, the Department of Agriculture spends more than half of its budget on food assistance programs for the poor and for children throughout the country. So in my portfolio, I manage the Food Stamp program, school lunch and breakfast, WIC, summer food program, food program on Indian reservations, food for the elderly, food for childcare centers, Head Start centers, and others-there are 13 programs all together, with Food Stamps, school lunch, and WIC being the largest. Also, I come here as a colleague of the people at the table and as a colleague of Dr. Novello's and Dr. Mason's.

One-stop shopping, as Dr. Mason said, is absolutely a must around the country. We agree totally on that issue in bringing all social services together, and as every speaker here said, that is a critical component. We have been sending a lot of books to Delaware because 12 centers there have combined all social services except for job training-WIC, Food Stamps, AFDC, Medicaid,

various child development projects and programs—all together in one office. I visited one of those offices; it was a pleasant place. One receptionist sees the clients, and all of their information is on a computer, which sounds simple and makes sense. But it was a huge undertaking for the State to convince the different Federal agencies involved to all participate in that project. It is a model, and we encourage many States—



we sent many people there—to see how that works, hoping that we can help them go more toward one-stop shopping in putting services together.

The President mentioned the immunization program. We've been very involved in that from the WIC perspective because it is one of the few places where very young children come within the system. If we can combine services and provide immunization services there at WIC clinics, it might be a very productive and helpful program to initiate. To that end, Dr. Mason and I have been working aggressively with health directors around the country to promote joint services for immunization and WIC.

Secretary Madigan yesterday mentioned direct certification for children in the school lunch program. This is a critical program, and I want to expand on it briefly. It doesn't make sense that a child may not be able to access a school lunch or breakfast just because of a bunch of paperwork that wasn't turned in. The way the system worked before direct certification, as you know, was that at the beginning of the year, the school sent home a form, through the child, to the parent that said, "Please fill out this form. Your child may be eligible for a free or reduced-price meal; tell us your income." Many times those papers don't get returned; a lot of parents don't want to fill out that paper; some parents may never get it; some parents may not be able to read it. So children end up not being in the school lunch and breakfast program, under which they may be eligible for free meals, because of paperwork. What direct certification is doing—and in the counties that have started this already, we've had great success, and it just began in September—is marrying computer lists. They marry the computer list of the kids enrolled in school with the families that are enrolled in AFDC and Food Stamps. They keep this confidential; it follows all the confidentiality requirements. But instead of getting a letter stating that "your child may be eligible," when this works—and it has worked so far in the many schools that have started it—parents get a letter at home that says, "Your child is eligible for school lunch." And, in fact, whether the letter ever gets home or not or the parent reads the letter is irrelevant because the

child gets the lunch or the breakfast. I would encourage people to go home and ask their school district if they have done this yet.

On the Food Stamp and AFDC side, I was at the Department of Health and Human Services managing the AFDC program before I came to [the Department of] Agriculture. One of the reasons I was asked to come is that the Administration cares about trying to put these programs together. Almost everyone who is an AFDC recipient receives Food Stamps, and the majority of Food Stamp recipients receive AFDC. It certainly makes sense to simplify the rules and regulations. The people who determine eligibility have thick books in every State for each of AFDC, Food Stamps, and Medicaid. Anyone having to learn the rules and how to work through them takes on a fairly remarkable chore. So what we are doing is working on the Federal level to identify eligibility requirements. So far, we've identified 52 eligibility factors that are different in the two programs, and we are working now to determine which ones we can change to make them the same or similar, so it will be easier for eligibility workers to manage, and ultimately easier for those who are in need to access the system in both programs.

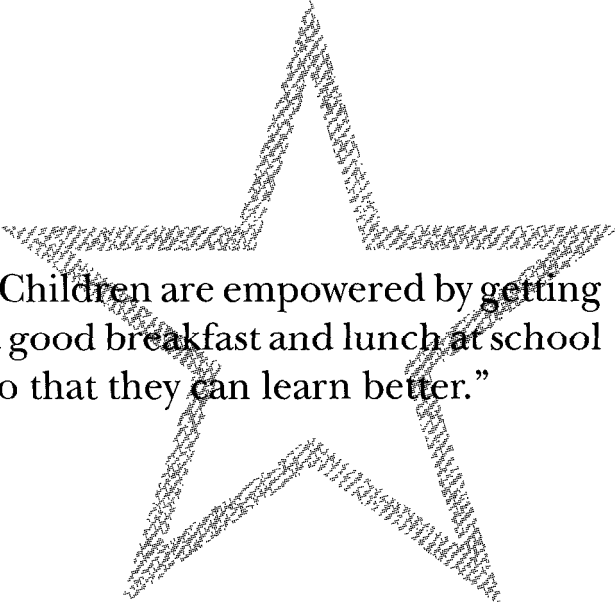
We learned from this process, however, that we have to identify these [needed changes], but we can't make all the changes ourselves. Many of the changes will require congressional approval, and we will be looking at changes we can make in the Federal Government and identifying when we need to go to Congress to request other changes.

I found out one of these changes when I first came to this job. In Alabama, I went to a Food Stamp office to apply for Food Stamps because I wanted to see how the system worked. I filled out lots of forms, and then the worker gave me one form that indicated I had to take it home and have my husband fill it out. I said, "Why? You're taking me at my word that I'm the head of the household, and all these other forms are OK for me to sign. Why do I have to take this one home for him to sign?" "Well, because that's the requirement. Every adult in the household has to sign this particular form." Well, that didn't make any sense to me, whatever; it was

a form dealing with whether or not we were U.S. citizens. So, I came back and asked questions about it, and a lot of the eligibility workers laughed. We'd been telling you that this was duplication for a long time. We proposed in the Farm Bill to Congress that they change this and eliminate the two signature requirement, and we got it changed. That was the good news. Then we found out that AFDC and Medicaid have the same requirement.

The final point on service coordination that I want to mention is what I think is the most exciting one we are working on, and that is called Electronic Benefit Transfer. We have now in the Food Stamp program a pilot project, and I want to explain what it is. This EBT, as it's called, is using the equivalent of bank ATM [Automatic Teller Machine] technology for the purpose of providing benefits for Food Stamps and, potentially, for AFDC, WIC, and other programs as well. The way this works is, or would be, that there are no longer food coupons in any community that undertakes this project. People get a plastic card and have a private PIN [Personal Identification Number]. The State or the county programs the amount of money that would otherwise be food coupon money into the account. When a client takes the card to the grocery store, the recipient runs this card through a machine at the checkout line, and it debits the appropriate Food Stamp account for that month. She could also use it, if it's an AFDC card, in a bank cash machine to take out her AFDC allotment, not necessarily in one lump sum, although that is certainly her option, but also in any amounts that she wants for the month.

We have, in the areas where we are testing this [EBT]—Reading, PA; Albuquerque, NM; Casper, WY (for WIC); Ramsey County, MN; and Baltimore, MD—only praise from clients who have been using this and from the Government and the private sector who have been using it as well, with one exception that I will mention in a minute. The people who use Food Stamps in AFDC have been thrilled with it, and the comments that we hear and the research that we have say that people like it. They like it because, first of all, it gives them security; people don't have to wait at the mailbox



“Children are empowered by getting a good breakfast and lunch at school so that they can learn better.”

(as they must if their food coupons or their AFDC is mailed) to make sure they get it. They don't have to cash the AFDC check in one lump sum and sometimes pay money to a check cashing place to get it cashed; it empowers them to be able to make decisions about how much money they want at each particular time. When they use this card in the grocery store, they don't have to deal with the coupons and counting out the coupons and dealing with it; they don't have to deal with anyone else trying to steal and use their coupons before they get to the grocery store. It's a quicker way to get through the system when they get to the grocery store.

In Wyoming, one woman at a cash register told me that she had been a WIC client and now she was working, managing the cashiers in the store. One of the reasons that she liked working there was that the card took the confrontation away in the line. Because (this program was in WIC, she said, but it could work in WIC or Food Stamps) the machine says what's eligible and what's not eligible, there doesn't have to be a battle between two people for that purpose. It's a benefit for the stores; it helps them move people through the line faster. It's a benefit for the clients on WIC because you don't get one voucher, one time a month. When you get one voucher once a month you have to use it all, and

that's tough if they don't have your type of cereal that day. With this new system, you can go back and use the card again; you don't have to buy all of your milk once a month and have it rot in the refrigerator, but you can go back over and over again. It's a real plus.

It's also a plus for the taxpayers, I have to say, because it will ensure that all of the money that the taxpayers are spending on food in our budget this year is \$34 billion—will be spent on food, and it will be an overall plus. What we have to do is ensure that it's cost effective, and the way that it's cost effective we hope, through our studies, is through combining services.

If we combine Food Stamps and AFDC and perhaps WIC, and perhaps someday other programs that we can save on the administrative costs, which I think was mentioned by a couple of speakers before, it will help us in the long run. That is the one problem: we have not yet proved that it will save administrative money, but we are determined to do that. States can implement this program for Food Stamps after April 1 of this year without a demonstration project.

As far as improving services, as Secretary [of Agriculture] Madigan said, President Bush for the last 2 years has increased the WIC program by proposing larger increases than any president ever—\$223 million last year, \$240 million this year. That combined total is going to help us serve more than 300,000 more people in the WIC program. Improving services in WIC goes beyond just putting more people in the program; it extends to improving the actual services that we provide.

One of the things that we've done in the WIC program is to look, for instance, at the issue of promoting breast feeding, and the issue of helping to empower mothers to make a choice between breast feeding and bottle feeding after they have given birth. Once when I visited a WIC store in Mississippi and went through the line looking at what I would buy, I told them I was a breast-feeding mom. I wanted to go through the line as a breast-feeding mom and pick up the food I would get. I picked up my peanut butter, eggs, cereal, milk, and my other products and then they said, “Oh, well, if you weren't breastfeeding, here, this is the formula that you would get.” Well, there was so much formula for the

month that I couldn't carry it out of the 'store! It is no wonder to me that only 10 percent of WIC moms breastfeed, when people may be thinking that they may be giving up this wonderful option of this great formula for their child. Not only would we like to empower women in making this choice, but also provide more nutrients for women who are breastfeeding. We filed a notice with the *Federal Register* asking for comments, and we intend to file a proposed rule as soon as we can to offer a separate package for breastfeeding moms in the WIC program.

In closing, school breakfast is critical for children coming to school ready to learn—all of our studies show that. Half the schools that have lunch also have breakfast; we can have more. We've been going around the country encouraging schools to offer school breakfasts, and it's really critical for children to come to school ready to learn. The summer food program is available—schools can offer it during the summer and private non-profit schools can offer it during the summer to help children have meals at school. All of these programs empower people. The WIC program empowers mothers to help make good decisions by education and nutritional support. Children are empowered by getting a good breakfast and lunch at school so that they can learn better. These programs are empowered by your comments and your direction to us.

The solutions? How can we work together? EBT can start in States for Food Stamps after April of this year. You can tell your State administrators and your county administrators that you think that they ought to have EBT. You can work with our regional offices. We will work with you, and I will take Jim Mason's lead and work with the public welfare administrators and communicate your comments specifically when I meet with the State Welfare Commissioners in 2 weeks. We can work together with changes that will simplify the application of AFDC and Food Stamps when we come up with proposals. We can work together because we need your help convincing our colleagues on the Agricultural, Ways and Means, Finance, Education, and Labor Committees. It would be helpful if we had similar rules for all of these programs. You also can help by going to

your school, and if you don't have school breakfast, tell the school, school board, or someone else who is a decisionmaker in your community that you want school breakfast for the children in your school. It's an entitlement program; the Bush budget anticipates at least 500 schools entering the program next year, but it takes community leadership and community support to get that done through the schools. Every person in this room, those of us at this table, be they the parent presenters or the people in the Administration, can do a lot to work together so that we can take your direction, the thoughts that we have, and implement. We can implement the President's direction to us to reorient government to better serve the needs of individuals. Thank you very much.

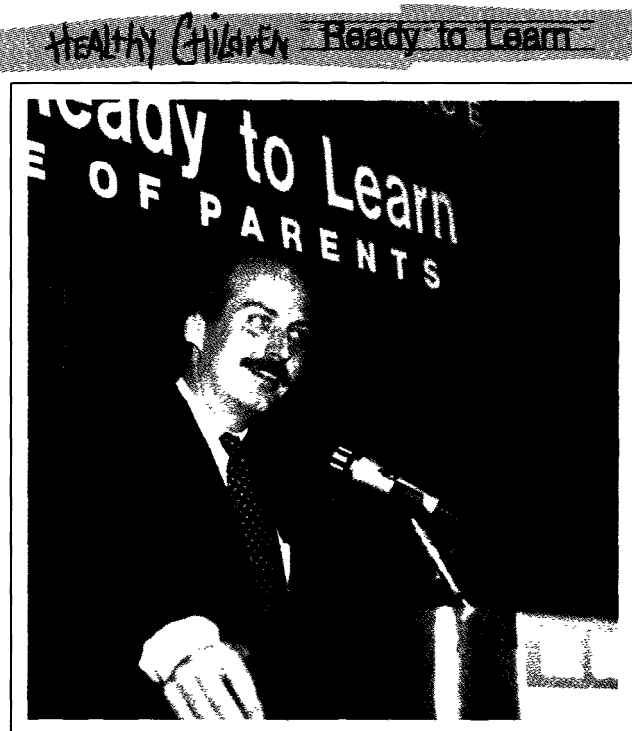
Wade Horn, Ph.D.

Commissioner

Administration for Children, Youth and Families

U.S. Department of Health and Human Services

It is a pleasure to be here today at the closing day of this Conference and I want to thank the Surgeon General for the invitation to participate here, but particularly to thank her for her wisdom in acknowledging and



recognizing the importance of the role of parents in helping to get their kids to school healthy and ready to learn. If we needed any validation of how critically important parents are, we've heard that from the three representatives here on the panel this morning.

I learn not just from parents but also from my own children, which I think all of us do. And it's because of my own experiences with my own kids that I have remained committed to trying to help as best I can in my present position, help programs help parents raise their kids, because kids are our future. I could be real brief here and I could say, "Guess what, I run Head Start. Head Start works; it's great," sit down, and everybody could applaud. Because Head Start is a great program; because it, in fact, embodies much of what it is that the parents talked about today. It embodies parent involvement and empowerment. Head Start has long recognized that parents are the first and most important educators of their children. And we've embodied that empowerment in the Head Start parent policy councils. Also, Head Start integrated health services with social services long ago. Do you know that Head Start makes arrangements for one of the largest delivery systems of health services to poor children in this country? Last year, more than 600,000 children in Head Start got free medical and dental screenings and followup treatment, as well as immunizations, through the Head Start program.

It has also been a leader in removing barriers to children with disabilities in terms of incorporating them and involving them in the program as well. Head Start has long recognized that children with disabilities need to be mainstreamed. We were doing that back in 1965. I was in the 5th grade, but in 1965, we were doing that. And we were a leader in that. In fact, today, almost 14 percent of all children enrolled in Head Start are children with disabilities. We even pay parents for their knowledge. Do you know that almost 40 percent of all paid staff in Head Start are parents of children either currently enrolled in Head Start or formerly enrolled? But I'm not satisfied, and we shouldn't be satisfied because there is still much to be done.

I am just going to mention three new challenges and initiatives we are undertaking in Head Start. First

of all, we need more money; we need to serve more kids. The President, over the last 4 years, has increased our budget by \$1.6 billion. That's an incredible achievement—that's real money, even here in Washington.

The second thing we need to do is increase services to adults of children enrolled in Head Start. In the old days, we had this naive belief that we could save children by taking them out of the home, working with them, and sending them back. We know that doesn't work. If we are going to help children, we have to help their parents. Over the last 3 years we have been improving the kinds and quality of services to adults of children enrolled in Head Start, particularly in the area of adult literacy. By the end of this year, we will have an adult literacy program in every Head Start program in this country. We need to do a better job of working with substance abuse problems where they exist in the families we serve. A recent study shows that at least 20 percent of all adults who have children enrolled in Head Start have a serious substance abuse problem. We need to do a better job, and we've been working with Dr. Mason and his staff, particularly in the Office for Substance Abuse Prevention and also with the Office of Treatment Improvement, to try to better coordinate services around substance abuse issues in Head Start, focused on the parents.

The third thing we need to do is to use Head Start as a wedge to increase job skills of the parents who have their children enrolled in Head Start, and we've been doing that in active collaboration with the new [Job Opportunities and Basic Skills training] JOBS program, the 1988 Family Welfare Act, and also with trying to merge or coordinate with the [Job Training Partnership Act] JTPA programs as well.

We have to recognize that times have changed. We have a number of homes with no parents at home when Head Start is done at 12 noon. We have to do a better job of coordinating with new childcare monies, and particularly childcare development block grant monies to ensure that, for those Head Start children who have parents employed outside the home, we can keep those centers open so those kids don't have to be bused across town to another center or, worse yet (and it does happen), sent home with the hope that somebody is there.

Finally, in terms of transition, we have to do a better job of moving kids from Head Start into the public schools. Larry Bell talked about making our kids ready for school, but he also said that we have to do a better job of making our schools ready **for** our kids. We do. Sometimes people point to Head Start, and they say, “Do you think it’s a success? It’s not a success. Because **you** know what? After your kid gets a year or two of Head Start, 5 years down the road, the gains start to dissipate.” And I say, “Sure. If the child graduates into neighborhoods that are riddled with violence, if the child graduates into homes that are riddled with substance abuse, if the child graduates into schools that are unresponsive to the needs of their children, what do you expect?” Head Start is not an inoculation against everything that can possibly go wrong in that child’s community. The fault is not Head Start’s; we need to do a better job of what happens to those children when they leave Head Start. That’s why it’s been so gratifying over the last 3 years to work with Jack MacDonald in ensuring that we make those connections between Head Start and the public schools. **Thank you for** the invitation to be here.

Christine Nye

Director

Medicaid Bureau

Health Care Financing Administration

I want to thank [parent presenters] Larry Bell, Sherlita Reeves, and Ellie Valdez-Honeyman for your comments this morning. It’s always so crucial and important that we hear the things that concern and interest you. Much of what I heard this morning had to do with the Medicaid program. The interesting thing about this Conference and what I’ve heard this morning is that it struck a relevant chord for me not only as a parent but also as an administrator of the Medicaid program.

As Dr. Mason said, I really didn’t know how to frame my remarks to you this morning, but it’s absolutely true that you want these things to happen. We want these things to happen too, so why don’t they happen? Let’s make them happen, and I think that is so important. Not only are we all as parents somehow affected or infected by the things that you said this morning; it goes deeper than that in other ways too.

For example, I’m the parent of two daughters, one of whom would have been 4 a month ago, but who, despite all the efforts of technology, died. And I’m also the parent of a little girl who will be 3 next week. So I have, personally, because of that, a deep commitment to many of the things that you do. Similarly, I can go through people in the Medicaid Bureau who are working on eligibility policy, on home- and community-based waivers, who also have a commitment to making things better, not only as professional people working in the Medicaid program, but who also are personally involved in some of the things that you are involved in as well. And that occurs not only at the Federal level—that we as people share these things—but also at the State and local levels.

I wanted to make a **few** comments today, and there are many things that I could say—so many things that we are trying to accomplish, so many areas where we are still falling short, so many things that we have to work on together. Medicaid is a massive program. It serves almost 30 million Americans, and 17 million of those are children. Children are disproportionately represented in terms of the number of those in poverty that are served. More children in poverty are served than adults or the disabled, for example. But despite that, and you all know this, it’s become such a visible thing of late, that we still serve less than 50 percent of people in poverty in this country despite the fact that we are spending over \$100 billion on Medicaid this year. So, Medicaid is receiving a lot of focus, not only through reforms in the Medicaid program but also, more recently, through the President’s proposal for health reform in terms of Medicaid’s key role in that system and also through additional key reforms that have to be made in Medicaid to make it more responsive to the American people.

There have been enormous changes in the Medicaid program lately in response to the concerns and issues you’ve raised. There have been expansions in eligibility. There are options and mandates in many States; as many as 20 States have enormously expanded eligibility for children to the maximum. There are changes for pregnant women and for infants, again,

enormous changes, in response to the concerns expressed by **you** and others. I think the concern that I've heard expressed repeatedly is about the dropoff or the "falling through the cracks." That problem is one that has not been addressed adequately so far, but again I think that the President's proposal is one that would address it.

In terms of service expansion, again, in Medicaid, there is an enormous recognition of some of the problems that are faced-increased flexibility in providing waivers to keep disabled and other children at home and not in institutions, and enormous changes in terms of the increased use of case management for various population groups in Medicaid, particularly for pregnant women and for children, but also for disabled children. What I consider the greatest child health reform in Medicaid since it was enacted is the enormous expansion in the Early Periodic Screening, Diagnostic, and Treatment Program, the EPSDT Program, the child health screening program in this country.

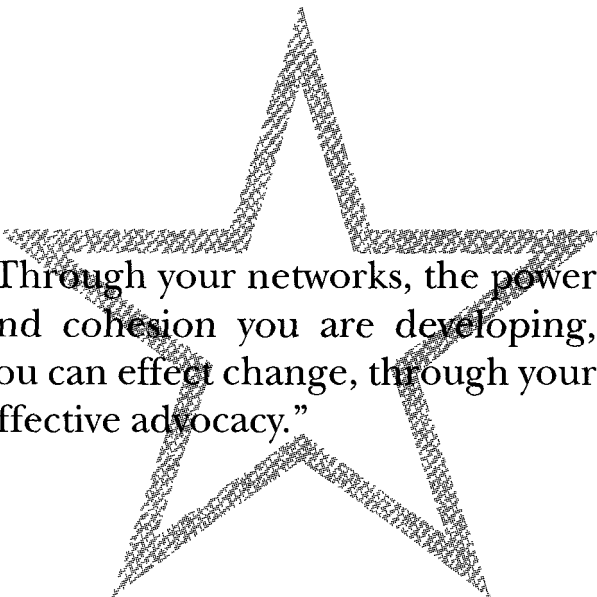
Along with service and eligibility expansion, there are also enormous concerns about access. Trying to streamline these application forms, getting eligibility workers out to places, and trying to expand the amount of dollars paid to community health centers and persons

providing obstetrical and pediatric services are all access issues in dealing with red tape problems, trying to overcome some of the barriers that physicians and other providers have with Medicaid. But again, as Dr. Mason said, these are things that you and I believe, and they are happening, but we need to continue to make them happen.

One thing that is a reality about Medicaid is that it is a Federal-overseen and State-administered program. States have **enormous** flexibility, which is both a strength and a weakness in the program as you try to make the kind of changes that are most appropriate for your communities. Through your networks, the power and cohesion you are developing, you can effect change, through your effective advocacy. I would suggest, as a followup to this conference, and maybe this is already planned, that you debrief your State Medicaid people about the kinds of things that you discussed and that came out of this conference.

We had a handout here; it was a one-page information sheet about Medicaid, and on the flip side was a list of all the regional offices for the Health Care Financing Administration and the people there whom we have designated to be responsible for maternal and child health issues. Those people are available to you to help you to approach and access the system. Also, we have a wonderfully knowledgeable person, Bill Hiscock, who will be more than willing and eager to answer your questions.

In terms of your questions, 'What are you going to do with these recommendations and all the time that we've spent and the heart-felt feeling that we have about changes that need to be made?' I have found this enormously helpful and also rejuvenating in terms of my commitment in trying to make some of these things happen, clarifying policies in what Medicaid will and will not cover and in transportation, and making sure that States are implementing the child health screening service appropriately. So, for that I want to thank you. I wish you much success when you return to your States and discuss at that level the things that you have discovered or heard.



"Through your networks, the power and cohesion you are developing, you can effect change, through your effective advocacy."

Lou Enoff

*Principal Deputy Administrator
Social Security Administration*

I accepted a call from Dr. Novello last evening, and I will tell you I'm glad I came. I'm glad I accepted, and it is a real pleasure to be here. I, too, am a parent. My youngest is graduating from high school this year, but I am also an expectant grandparent; I don't have a picture yet, but I have a sonogram, if you'd like to see that. We're anxiously awaiting that. I've been involved in the activities of all three of our children in the schools, in the curriculum council, and in the PTA, and I just want to say, keep up what you are doing.

I'm here not only because I'm a parent. You're probably saying, 'What the heck does Social Security have to do with kids?' Well, most people think of Social Security as a retirement program. And we are, I think, a very successful retirement program. We have a budget of over \$300 billion, and we pay 40 million checks every month on time—we've done that for more than 50 years. We have 1,350 offices around the country, where I assume you all get **very** good service when you go there. We have people who serve you with compassion and efficiency. We're proud of that. But many people don't realize that we at Social Security also have a great deal to do with children. Every month, we pay more than \$1 billion to more than 3 million children under one of the Social Security programs because, in addition to retirement, Social Security has a survivor's program and a disability program. We pay children of retired workers, children of disabled workers, children who are themselves disabled, and children whose parents are deceased and where there is a need for income. So, every month we do pay 3 million kids more than \$1 billion.

Let me speak for a moment about some of the things that we have done in response to the questions that have been raised here. First, in terms of access, a few years ago Social Security installed an 800 telephone number, toll free, nationwide, 12 hours, from 7 a.m. to 7 p.m., so that you can call us from anywhere in the country. You'll get someone who will help you, including bilingual help. If you need a referral, we can refer from there. We're talking about Social Security



business, generally. We can't refer you for everything, but we will help you if you call us on that 800 number. We can make an appointment for you in one of the offices if you need to come into the office. We're trying to bring that service to where people can access it from their home, if they need it.

Second, I would mention the program that we administer called SSI, Supplemental Security Income. It reaches another 4 or 5 million eligible people. Commissioner King launched an SSI Outreach Program. We recognize that we in government cannot do this alone. We cannot find the people who might be eligible for this program and who have a needs base there. But we know that you in the community do know about people, so we've begun an outreach campaign in all of our local offices where we try to educate those who are involved in the community to help us find those who may be eligible for the program. It's been very successful, and we've had a 20 percent increase in applications in both of the last 2 years, and we are continuing to forge those partnerships with community organizations. We need your help, and we'd be glad to work with you in any of your organizations in helping to find persons who may be eligible for SSI.

Also in the last 2 years, we have launched a special program for children with disabilities who may be

eligible for SSI. Some of you may have heard of the Zebley court case. In that situation, we've developed a whole new procedure for determining disability in children. We've worked with pediatricians, school social workers, and others to define what disability means in a child. We've had a lot of help from the Public Health Service, and we've had a lot of input from community groups. During the last year and a half, we've taken 450,000 applications from children with disabilities, and we've increased the number of persons receiving those benefits from about 200,000 to more than 400,000.

You mentioned one-stop shopping. Working with our colleagues in agencies represented here, we've begun to integrate our services. We are locating our offices whenever we can together with other State, local, and Federal offices that have the same clientele that we do. Secretary Sullivan has launched a program of integration of services, and all of us in [the Department of Health and Human Services] HHS are working closely to try to coordinate our service delivery at the local level. We do have a standard of service. For the first time, we have published standards of service for our offices, and we have just begun receiving public input to that. We will be modifying that as we go along, and we will be publishing our goals and how long it should take you to receive service in a Social Security office. We issue a Social Security card, for instance, in 10 days now. It used to take us a month to do that. We have other goals, too. We are trying to determine what is most important to the public so that we can put our emphasis in that area. I think it was Ms. Reeves who said, "What will we do, if we don't like what we hear?" Well, I hope you'll call us, if you have a problem or a concern about Social Security. I mentioned the 800 number; if you call that number and don't get satisfaction, I hope you'll call me. My number is 410-965-9000. We are your servants here; we are here to help you.

Chapter 25

Commitment of Our Leaders



Chapter 5

Commitment of Our Leaders

President George Bush and prominent members of his administration expressed their personal commitment to the Healthy Children Ready to Learn Initiative by attending the Conference and speaking to the participants. President Bush delivered his keynote address in the afternoon of the first day. In addition, each day of the Conference began with a keynote speech given by heads of the cosponsoring Government agencies: Secretary of Health and Human Services Louis Sullivan; Secretary of Agriculture Edward Madigan; and Secretary of Education Lamar Alexander. Roger Porter, Assistant to the President for Economic and Domestic Policy, also addressed the participants. This section contains their remarks.'

George H. Bush *President of the United States*

Might I just say at the beginning of these brief remarks that I am very proud of Lou Sullivan and what he's doing as Secretary of Health and Human Services. He's doing a superb job, and we all are grateful to him. And let me just say it's a pleasure to be here today to help launch this historic Conference.

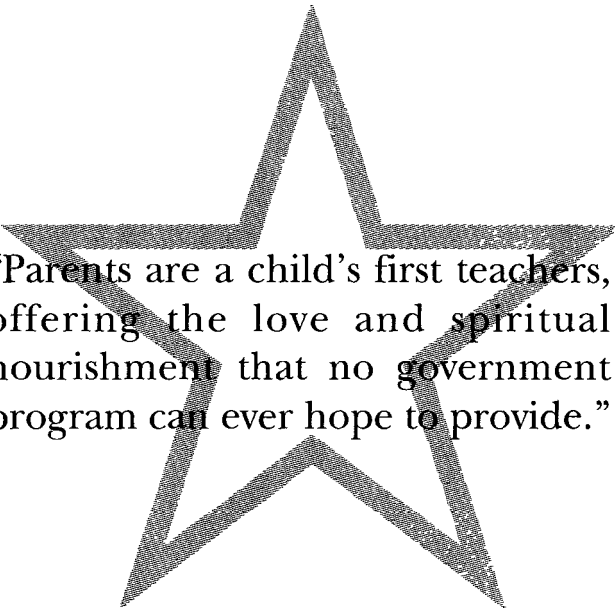
I particularly want to thank our Surgeon General, Antonia Novello. She has inspired people all across the country with her example and her message. And she sums it up this way, better than anyone: "All children have a right to be healthy." Then she says, 'We need to speak for those who cannot speak for themselves.'

That's why you've gathered here this week, and you've come to lead a great movement of parents, doctors, teachers, public programs, and private enterprise—a movement destined to transform America. Here's our goal: By the year 2000, every American child will start school healthy and ready to learn. Our success will provide a lifetime of opportunity for our children.

'Some of these remarks have been edited for clarity.'

It will guarantee the health and safety of our families and neighborhoods, and it will ensure that America remains the undisputed leader of the world.

Now, I am proud that our administration is part of this movement. In this administration, families come first. We're proud to join hands with people like Trish Solomon Thomas, who has come from New Mexico to be here this afternoon. She has two children, both of



"Parents are a child's first teachers, offering the love and spiritual nourishment that no government program can ever hope to provide."

them with special health needs. She perfectly expressed the spirit of our movement when she said, "I used to be shy, but I had to learn to stand up for my kids." And that's why we're here, to stand up for our kids. We will not let them down. Our movement draws its strength from Trish and the millions of parents like her. The title of this Conference says it all: "Healthy Children Ready to Learn: The Critical Role of Parents." Parents are a child's first teachers, offering the love and spiritual nourishment that no government program can ever hope to provide.

If I can brag for just a minute here today, you may know of Barbara's work promoting literacy. I'm very proud of her. She wants to help parents understand just how important it is to read to their kids. When parents read aloud to their young ones, they open their children

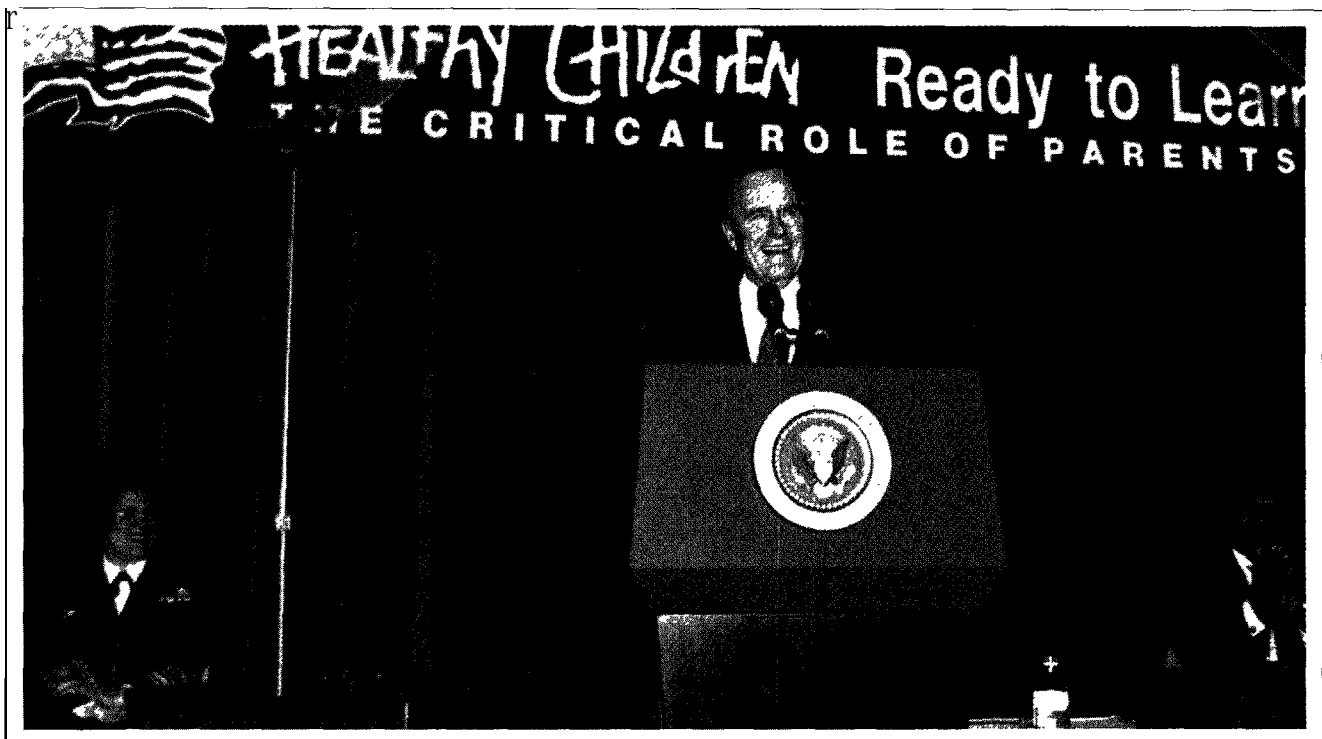
to the joy of a larger world; they teach the self-assurance and curiosity that comes from learning. Barbara asked me to extend her best wishes. She's now on a learning program, an education program right this minute, in the State of Mississippi.

Our movement instills the habits of good health: wholesome nutrition, sound hygiene, and protective measures like early immunization. Parents know that learning and health are two sides of the same coin. Again, parents, families, and communities are the key. But government can help and must help. Last June, for example, Dr. Sullivan and I, with able advice from Dr. Novello, took steps to ensure that no American child is at risk from deadly diseases like polio, diphtheria, and measles. We launched an initiative to support childhood immunizations, especially immunizations for kids in the early years of life. Now, that's a crucial step toward meeting our goal. I'm proud we've been able to help. Since 1988, we've more than tripled the dollars for Federal immunization efforts, from \$98 million to \$297 million for 1992.

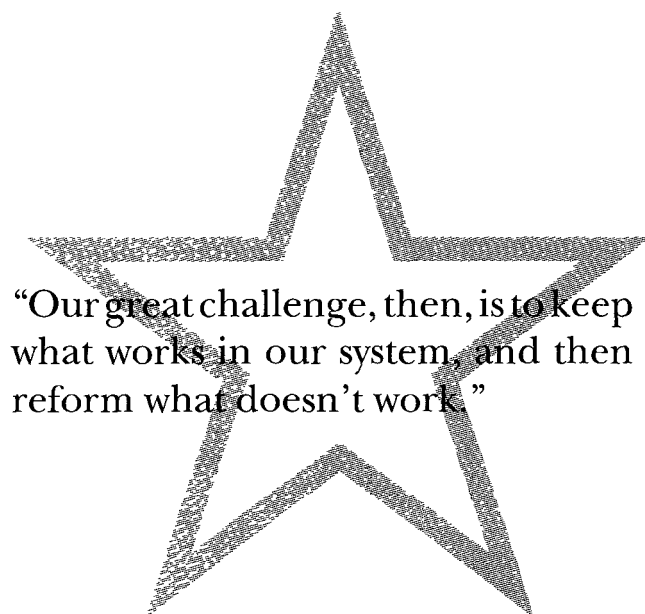
On Friday, Dr. Sullivan and the Surgeon General and I were out in San Diego, and we had the privilege of visiting Logan Heights Family Health Center to see firsthand the benefits of this initiative. We spoke with parents and community leaders, and every one of them stressed the importance of early immunization in preventing illness. Logan Heights is, one of many, I'm sure, a perfect example of what can be done if concerned individuals set their minds to it. The Center was founded by a wonderful woman named Laura Rodriguez, who's become one of our administration's Points of Light, helping others and setting an example in the process. Laura saw a need, and with hard work and dedication, she rolled up her sleeves and did something about it. Logan Heights now serves 75,000 patients a year. So I say, "Thank God for people like Laura. She's an example for all of us." There are many, many other examples right here in this room.

For those kids who need a head start in preparing for school, we've made sure that they'll get it. In the last 3 years, we have almost doubled the funding for Head Start

HEALTHY CHILDREN Ready to Learn



programs, and this year, I have proposed the largest single increase in Head Start's history: \$600 million. This year's increase will ensure that 157,000 more kids will be able to start school ready to learn. Head Start brings children and parents into the classroom and into the learning process. Head Start works because parents take the lead. You may not know this, but volunteers in Head Start outnumber



paid staff by eight to one. Head Start works because people care. We're making sure it continues to work. If it's good for America's kids, it's good for America.

These are important steps. But there's more to do. We must address the larger issues of American health care. Last week, I proposed a four-point plan to do just that. Every American family must have access to affordable, highquality health care.

I don't need to tell you that the American health care system has problems. The crisis has probably touched many of you right here in this room. Right now, more than 8 million children go without health insurance because skyrocketing costs have placed coverage beyond the reach of their parents. And even parents who are covered worry about losing their family's insurance if they move on to a different job or, worse still, lose the job they have. You shouldn't have to live

with this kind of uncertainty. No American family should, and my proposal would put an end to that.

Yet I think we should keep one thing in mind. It's important to remember that, for all its problems, our health care system still provides the best health care in the world. That's why people from all over the world come here seeking better care. Most often they're trying to escape health care systems in which the government dictates how much care you'll get and what kind you'll get and when you'll get it. In America, that's unacceptable.

Our great challenge, then, is to keep what works in our system, and then reform what doesn't work. We must maintain a maximum freedom of choice and the highest quality care. At the same time, we must make sure that our children have access to health care their parents can afford, sick or healthy, rich or poor.

That's what this four-point plan does, and let me just briefly spell it out for you. First, I want to make health care more affordable and accessible. I want a \$3,750 tax credit for low-income families to help them buy health insurance; for middle-income families, I've proposed a tax deduction for the same amount. Poor people, those who don't file taxes, also would be covered under this plan.

Second, to cut costs, we will make health care more efficient. The math is simple: The larger the group being covered, the lower the cost per individual. So we've proposed health insurance networks that bring companies together to cut administrative costs and make insurance affordable for working parents.

And third, we must cut out waste and abuse. We can start with medical malpractice lawsuits that drive up the cost of care for everyone. A doctor pestered with frivolous litigation ends up passing his legal costs right along to you, the American people, and right along to the patient. When you go to the doctor, I don't want you to have to pay a lawyer, too. Just pay the doctor.

Finally, we must slow the spiraling costs of Federal health programs. These costs are rising far beyond the rate of inflation, and that only endangers important benefits while making less money available for more pressing needs.

There it is. A common-sense reform that will maintain high-quality care, cut costs, ensure maximum freedom of choice, and give every family-rich or, poor, sick or healthy-access to health care. I know how important this is, particularly for parents who have children with special needs. My plan will ensure that you can change jobs without endangering the health insurance on which your child depends. We're building on our system's strengths. We're avoiding the pitfalls of nationalized care, the kind that people from all over the world come to America to escape.

All these approaches for meeting our goal of healthy children ready to learn must build on a basic truth, that, in this country, families come first. Government programs that overtake the rightful role of families and communities, deny them the freedom of choice, or bind them up in red tape are simply unacceptable.

Our movement is about strengthening families. Over the next few days, I'm told you will continue a great national dialog, share information, explore new ideas, and then return to your communities to lead the good fight. Your commitment is an inspiration, and I thank you for inviting me to get a feeling of it firsthand.

May God bless all of you. Thank you all and may God bless America. Thank you very, very much.

Louis W. Sullivan, M.D.
Secretary of Health and Human Services

Good morning. It is a sincere pleasure to welcome everyone to the "Healthy Children Ready to Learn" Conference. I'd like to take a moment to commend my colleague, Dr. Antonia Novello, who has been working diligently during her tenure at the Department of Health and Human Services to improve the health and well-being of America's children. This very timely and important Conference is the culmination of 18 months of planning among the Office of the Surgeon General, the Departments of Agriculture and Education, the National Governors' Association, and so many others. I am confident that this Conference will play an essential role in our departmentwide effort to improve school readiness.

You know it is not often that we policymakers in Washington stop to confer with the real experts about the challenges facing American children. But today we are. Today, we are convening parents from every State in our Nation. Together with educators and health professionals from the front lines, we can network, share promising programs, and strategize about how we can meet the President's first National Education Goal that "by the year 2000 all children in America will start school ready to learn."

As we all know, a good beginning is often the key to success. This is especially true when we speak of children. As parents, health care professionals, psychologists, educators, and others who work with children will attest, the experiences of childhood shape the course of a lifetime. This sentiment was beautifully captured by John Milton, who wrote: "Childhood shows the man as morning shows the day."

Healthy Children Ready to Learn

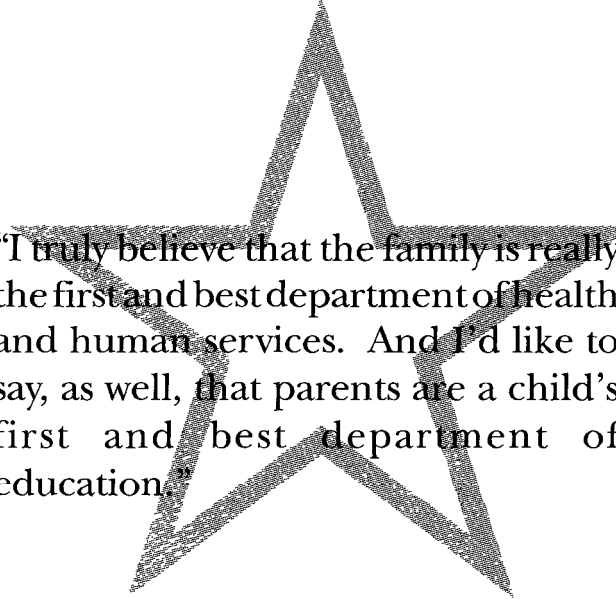


What determines whether a childhood is a beautiful sunrise in warm tones of amber and crimson, or a grim, colorless dawn? First and foremost, a child needs to be secure in the love of his or her parents. A father who reads to his child each night before bed, or a mother who proudly displays crayon masterpieces on the refrigerator, is really laying the groundwork for a positive school experience. In addition, a warm, colorful childhood is a healthy childhood. Children's health and their ability to learn are mutually dependent. Being ready to learn depends upon a child having enough to eat, being protected from preventable diseases, growing up free from environmental pollutants, and having access to health care. Helping parents to provide a healthy childhood for their children is a central part of the mission of my Department.

In his fiscal year 1993 budget, President Bush has provided us a blueprint for action. The President's budget proposal has three areas of emphasis: First, we must invest in children; second, we must focus on prevention; and third, programs must empower parents.

Investing in Children

Investing in children is simply good health care policy. The time and resources we devote to children now will pay continuous dividends in the future in the form of healthier and more productive citizens. In recognition



"I truly believe that the family is really the first and best department of health and human services. And I'd like to say, as well, that parents are a child's first and best department of education."

of this fact, the President's budget proposes to increase investment programs serving children to \$100 billion, up from \$60 billion in 1989.

Healthy Start

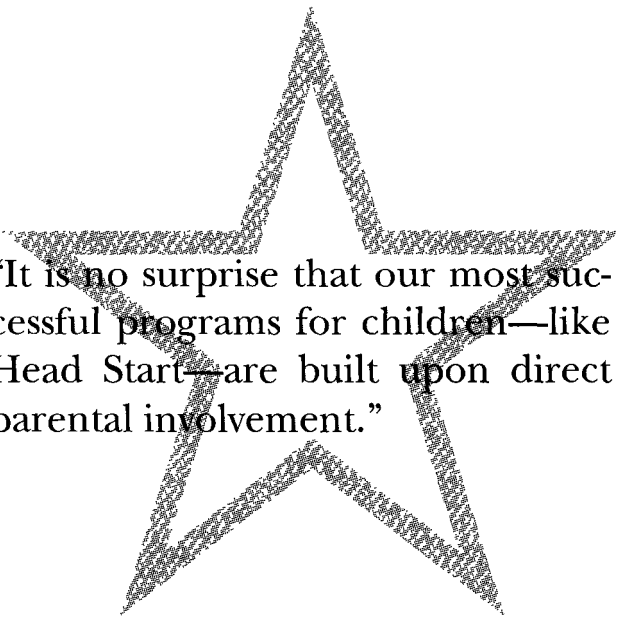
The first few years of life, beginning in the womb, are the most crucial period of child development. Therefore, if we truly desire to invest in the next generation, we must begin before the child is even born. We must begin by making sure every mother receives early, quality prenatal care. Overall, nearly 25 percent of all women and nearly 40 percent of Black and Hispanic women do not receive prenatal care in their first trimester of pregnancy.

Lack of prenatal care is a contributing factor to this Nation's disgraceful infant mortality rate. Despite spending more on health care than any other nation, the United States remains 24th among nations in the rate of survival of infants. Each year, 40,000 American babies do not live to celebrate their first birthday. Black babies are more than twice as likely as white babies to die.

The President and I have made infant mortality a national priority by developing a new infant health initiative, Healthy Start. Our strategy is to concentrate resources in 15 communities with stubbornly high infant mortality rates. Each community is given the flexibility to create a mix of services tailored to the needs of their population. We are requesting \$143 million to provide these 15 communities with the resources necessary to fully implement their detailed strategies for reducing infant mortality rates by at least 50 percent over a 5-year period. We will use the knowledge gained from these demonstration projects as a model for other communities across the Nation.

Focus on Prevention

The President's budget also will focus resources and attention on preventive health programs. Common sense argues that it is better to invest in prevention and screening programs than to wait until the Advanced stages of disease, when treatment is more complicated and more costly.



“It is no surprise that our most successful programs for children—like Head Start—are built upon direct parental involvement.”

Immunizations

Childhood immunizations are among the most cost-effective prevention activities. A \$1 investment in measles-mumps-rubella vaccine may return \$14 in avoided medical care costs. We can be proud of the fact that 97 percent of American children entering school are immunized. However, to be fully protected, children need to be properly immunized by the time they are 2 years old. Our rates among preschoolers are much lower, and in some inner-city areas, the immunization rate among 2 year olds is an abysmal 20 percent.

That is why the President has requested \$52 million for our immunization activities—an increase of 148 percent since 1989. My Department will use this increase to target those children most at risk. These dollars will translate into 6.7 million polio vaccinations, 4.1 million measles-mumps-rubella vaccinations, and 2.6 million hepatitis B vaccinations.

Lead Poisoning

Lead poisoning, the most common environmental disease of young children, is another preventable disease. As many as 3 to 4 million American children under 6 years old may have lead levels in the blood high enough to cause developmental delays, learning disabilities, behavioral problems, decreases in intelligence, and even death.

Low-income, minority children growing up in urban areas are most at risk of having dangerously high levels of lead in their blood. The President's budget requests \$40 million, a 90 percent increase, for CDC Lead Poisoning Prevention Grants. These grants will support about 30 statewide lead poisoning screening programs.

Empower Parents

The third emphasis of the President's budget is the critical role of parents and the need to support programs that empower parents. I truly believe that the family is really the first and best department of health and human services. And I'd like to say, as well, that parents are a child's first and best department of education.

Educators often speak of the “hidden curriculum of the home” to describe the important lessons we learn during our first few years of life. We learn that our parents love us very much, and that gives us a sense of security. We learn how to share, and we learn right from left and right from wrong.

These are not easy lessons to teach. And all too often this learning does not occur because parents cannot, or do not, attend to the needs of their children. It is no surprise that our most successful programs for children—like Head Start—are built upon direct parental involvement.

Head Start

Head Start has won the confidence of the American people. It is known as a program that works and a program that is worthy of our tax dollars. Many of you in the audience are familiar with Head Start; some may even serve on parent councils, which guide the operations of the individual centers.

President Bush, a firm believer in the value of Head Start, has proposed the largest single-year funding increase in the history of Head Start. The \$600 million he has requested will serve an estimated 157,000 additional children in 1993. These additions would mean that funding for Head Start has more than doubled since President Bush came to office. This unprecedented increase in Head Start supports participation of all eligible and interested disadvantaged children for one year.

The President's Health Care Proposal

In addition to targeted interventions such as Head Start and Healthy Start, the President announced last week his health care reform proposal. Under the President's plan, the middle class will get help to pay for health care through a new income tax deduction. For poor families, the plan guarantees access to health care through another new feature: a health insurance credit. In combination, these tax provisions will help more than 90 million Americans and cover 95 percent of the uninsured.

This morning I've outlined the tremendous new resources that the President wants to make available for children. But more money alone is not enough. The critical element of any initiative to help children is parents. Unfortunately, for reasons ranging from parental exhaustion to preoccupation with careers, children today spend 40 percent less time with their parents than they did in 1965—an average of only 17 hours a week! To put that figure in perspective, American children spend an average of 25 hours watching television each week.

I'm encouraged to see so many parents and child experts gathered for this Conference. Over the next few days, you will have the opportunity to use your combined expertise to move this Nation toward the goal that all children will begin school ready to learn. To borrow again from Milton, you will have the opportunity to make childhood a warm and radiant sunrise, ushering in a day of golden hope.

Thank you all. Godspeed to all of the Healthy Children Ready to Learn participants.

Edward Madigan *Secretary of Agriculture*

Nutrition is basic. All things can be possible for a child who is well fed; very little is possible for a child, or a pregnant mother, or anyone for that matter, who doesn't get the nutritious foods we all need to grow, to learn, and to excel. It's our job to get that information to you and before the public and into everyday practice. There are 64 million children in the

United States today, and all of them share this need. That's why we're here this morning.

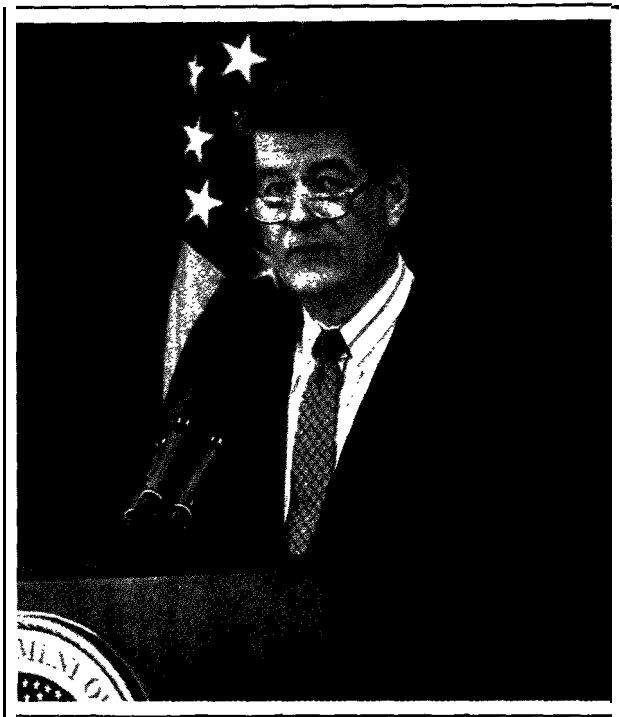
The President recognized the importance of a strong nutrition foundation in his education initiative. The first of his six National Education Goals is that "By the year 2000, all children in America will start school ready to learn."

To achieve this, we have to ensure that they receive the nutrition they need for healthy minds and bodies. That responsibility begins before children are born. Working with mothers, we must ensure that the number of low-birthweight babies is significantly reduced through good prenatal care.

Although we are investing large amounts of money and effort to help, it's the parents of children in these programs who have the primary role to play in their care and feeding. One of our best programs for reaching both children and the parents of children at risk is the Supplemental Food Program for Women, Infants, and Children, or WIC. This program provides supplemental food and nutrition education to low-income pregnant, postpartum, and breastfeeding women; infants; and young children—all at nutritional risk. WIC serves one in three babies born every year. That's about 5.3 million participants this month alone. And our highest priority is low-income pregnant women and their infants. What's more, WIC has become a gateway to other **government** services, especially health care. Through WIC, pregnant women are learning about and obtaining health services they need. Local WIC agencies refer applicants to Medicaid if it's likely they're eligible.

WIC is an adjunct to health care that participants receive at local health clinics. For example, WIC personnel promote breastfeeding among program participants, coordinate with State and Federal immunization programs, and provide alcohol and drug abuse prevention education and referrals.

WIC is cost-effective. A major study done in 1987-88 in five States showed that Medicaid-eligible pregnant women who participate in WIC do indeed have healthier babies than low-income women who do



not participate. Every dollar spent on prenatal WIC care was associated with a Medicaid savings of between \$1.92 and \$4.75 for newborns and their mothers.

Last year, the President highlighted WIC as a major priority to ensure that children enter school healthy and ready to learn. He requested the largest budget increase for WIC of any president. An even larger increase, \$240 million in 1993, will enable WIC to reach 5.4 million women, infants, and children each month. Virtually all low-income pregnant women and infants who are eligible are enrolled in the program. This 2-year effort will extend WIC benefits to nearly 500,000 more people.

This year, President Bush is requesting a \$600 million increase for the Head Start Program. Here again, we at the Department of Agriculture work together with another Federal program. Head Start provides education services under the Department of Health and Human Services; the Department of Agriculture provides the meals and snacks.

Our counterpart program is the Child and Adult Care Food Program, which concentrates on preschool children, ages three to five, in non-residential childcare centers and family daycare homes. Today, the program is operating nationwide, in 170,000 childcare centers and

daycare homes. It's been a fast growing program, and many of your preschoolers participate. Next year, we propose to spend \$1.17 billion on the Child and Adult Care Food Program. We expect to serve 100 million additional meals in 1993, due in part to the continued expansion of Head Start programs.

Of course, the program your children probably participate in when they enter kindergarten or first grade is the National School Lunch Program. Through this program, schools serve almost 25 million lunches each school day in virtually all the public schools and in most of the private schools. Half of those are free or at a reduced price. Our efforts to change this program are aimed at focusing our limited resources to those who need them the most, without sacrificing the program benefits to all of our Nation's children.

Once again this year, the Bush Administration is proposing a restructuring of the reimbursement for the School Lunch Program. Our proposal would reduce the cost for reduced-price lunches by a quarter, so that a student in that category could get a nutritious meal for no more than 15 cents. For reduced-price school breakfasts, the cost would be reduced to a dime. More well-off children would find their per-meal costs increasing by \$.06, a small price for such an extended benefit to those truly in need. This proposal would enable us to reach 250,000 more children who are currently eligible to purchase meals at a reduced price but are not participating.

This year, we've made it much simpler for schools to establish a child's eligibility for free school lunches and breakfasts. We've started a direct certification system under which schools now communicate directly with local welfare offices. If a child comes from a family receiving Food Stamps or benefits under the Aid to Families with Dependent Children Program (AFDC), the child may receive free school lunches and breakfasts. Parents are not required to submit an application. As a result, schools report that they're serving more free lunches to eligible children than ever before. We don't yet know how many more are benefiting, but indications are the number is substantial.

As many of you may already know, I am working to see that schools and daycare facilities begin to comply with

the 1990 Federal Dietary Guidelines for All Americans. Among other recommendations, these guidelines suggest that children and adults eat a diet in which 30 percent or less of the calories come from fat. We're working to achieve that goal in the school lunch and breakfast programs, and we're making progress. To assist in this effort, we're conducting demonstrations in California, Colorado, Louisiana, Ohio, and Tennessee to test how schools can modify their menus to reduce fat, salt, and sugar and still keep students eating school lunches. We are testing or have tested four different types of low-fat hamburgers in six States last year, and the comments coming back from the schools were very favorable.

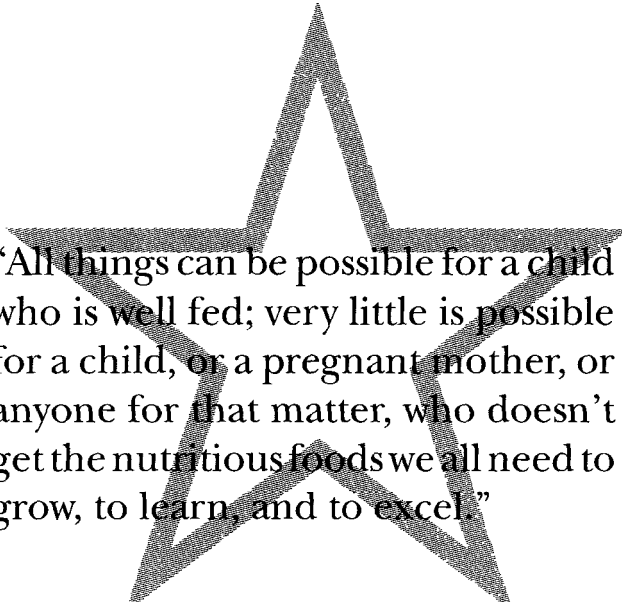
In a few months, we will issue a publication and instructional videos to give cafeteria workers additional information they need to offer meals that meet the dietary guidelines. The new dietary guidance will be provided to more than 275,000 child nutrition program operators-some of you are here today-in more than 90,000 school districts across the country. I have promised to provide schools with the tools they need to comply with the dietary guidelines by 1994. Our goal is to have at least 90 percent of all lunch and breakfast menus in line with the dietary guidelines by the year 2000. I'd like to do a little better than that, and sooner.

Some of you are parents of children who will be participating in the School Lunch Program, and you need to be involved with your school and its lunch program. Just as Head Start owes much of its success to parent involvement, the same holds true for school lunch. Our most successful school lunch programs are those where parents are involved.

Besides school lunch, the School Breakfast Program serves almost five million children daily. And about 80 percent of school breakfasts are served free.

The largest of our food assistance programs is Food Stamps. Eighty percent of those benefits go to families with children and about half of all Food Stamp participants are children. More than 12 million children receive Food Stamps each month. Beyond that, three out of four households with children also receive benefits from at least one other food assistance program. In 1993, the Department of Agriculture expects to spend almost \$23

billion on the Food Stamp Program alone. Food Stamps are available for every needy person who meets the qualifications and enrolls in the program.



"All things can be possible for a child who is well fed; very little is possible for a child, or a pregnant mother, or anyone for that matter, who doesn't get the nutritious foods we all need to grow, to learn, and to excel."

There are, of course, other food assistance programs. During the summer months, the Department of Agriculture provides meals for children in low-income neighborhoods. In 1993, this program will provide about 100 million meals. We also distribute food packages and commodities. Food packages are distributed on Indian reservations and to the homeless. We also have programs that distribute bulk commodities to orphanages, hospitals, soup kitchens, food banks, and meals on wheels.

The food assistance programs do a very good job of providing needy people with food. But they need to do more than that. We must make use of these programs to teach people about the critical relationship between diet and health. We need to do more than provide good food. We need to provide food that is good for them in the right mix. We need to help them understand the difference.

The Nutrition Education and Training Program, known as NET, supports nutrition education for school food service personnel, teachers, and students. NET has done a good job in the Nation's schools. But some areas deserve more attention-such as educating

preschoolers in the Child and Adult Care Food Program. The President's 1993 budget requests a 50 percent increase in NET funds next year. These new funds will be used to expand nutrition education and training to childcare providers who serve very young children. We will develop preschool curricula as well as materials that show care providers how to serve safe and nutritious meals and snacks.

I want to mention the National Food Service Management Institute, sponsored by the Department of Agriculture. The Institute began operations at the University of Mississippi in 1990. It helps school lunch operators improve both the quality of meals and the operation of child nutrition programs. We expect the Institute to be a valuable source of consistent training and research-based information.

From the beginning, WIC has made nutrition education an integral part of the program. In 1993, we will spend \$115 million on nutrition education to help parents learn about the right foods to serve their children.

To further improve the nutritional status of the neediest WIC participants, we have requested \$12.5 million for our Extension Service to provide intensive nutrition training for the most needy. We will use these funds to serve 50,000 new WIC participants, in addition to the 91,000 now served through the Expanded Food and Nutrition Education Program.

The President's budget also proposes \$4.5 million in State grants to develop and distribute training and nutrition education materials for hard-to-reach adults. The objective here is a nutrition message sensitive to income, educational levels, and cultural preferences.

The breadth of our food assistance efforts affects many people. In total, this month, we'll reach over 50 million Americans. This effort begins with informed, engaged parents who are taking an active role in the programs that affect their children. I urge you to work locally to see that these programs succeed. Everyone who can and should be enrolled in these programs needs to be enrolled. They are among the most successful and helpful in government. In many cases, it takes you to make them work. Keep at it. There are 64 million children depending on you and on me. We can make

a difference in their future. It's our future as well. The stakes are too high for us not to succeed.

I thank you, and God bless you.

Lamar Alexander *Secretary of Education*

Can you imagine a more irrepressible Surgeon General than Antonia Novello? She called me a few months ago, and then she came by to see me. I said, "Now, I will be glad to come see you," and she said, "Oh, no, I want to come see you." So she came over to see me, and she told me about her ideas for this Conference and how she wanted to focus the idea of healthy children with the first National Education Goal—children ready to learn—and how she wanted the various Departments, those of us in the Federal Government who work in these areas, to join in and to work with the Governors. But more than anything else, we wanted to invite and bring together people from around the country, not all of whom were experts in working with the Government every day, but people who were advocates. Some are experts in working with the Government every day, but many are not, and I'm sure it's been a very **free-flowing**, spontaneous, useful 2 or 3 days. I got the sense of that just this morning in the few moments I talked with you.

I think it's good to have conferences when you don't know exactly what the result will be; when you have people who aren't programmed necessarily; when you have an opportunity to hear a lot of different people and learn some things you might not have known before and consider some things that might be different than things you considered before. I think in an opportunity like that you can make more of a contribution than you can in something that is staged.

I know that many of you worked late last night with your thinking and your ideas, and you will probably be wondering, "Now what? What about all of that work, all of that enthusiasm, all of that talk—will it make any difference?" Well, the answer is, of course it will make a

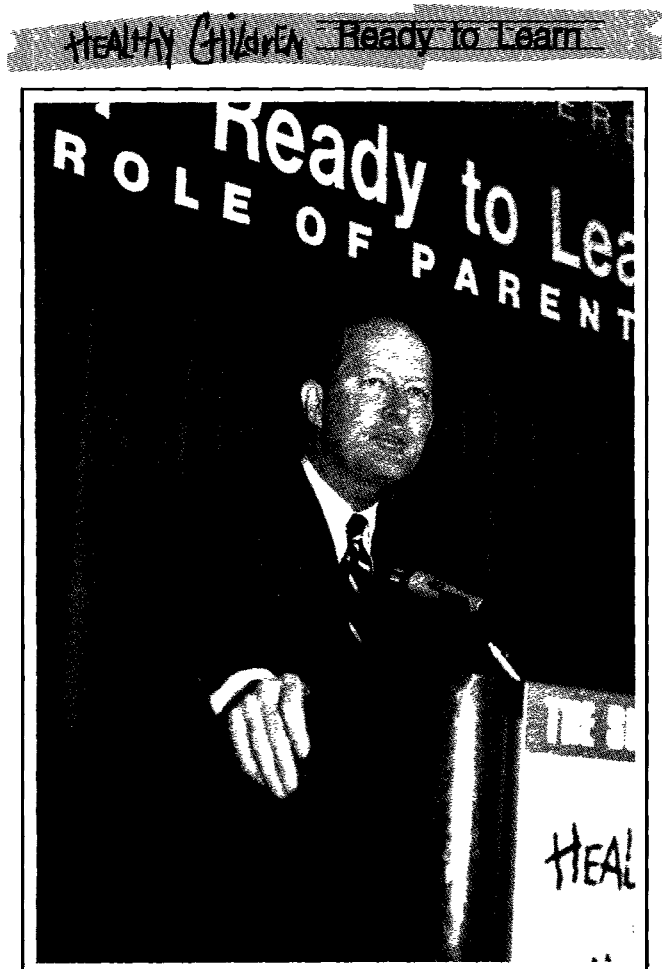
difference. You ought to get a sense of that **from** the crowd that you've attracted here in the last few days. The President's been here; lots of people have been here. They're paying attention, I think, to your presence. So your ideas will make their way back into Government, into the States that you come from, and hopefully, and maybe most importantly, which is what I'd like to talk about, back to the communities in which you live.

We like to call them the America 2000 communities. You may call them whatever you would like, but in the end, that's where the results really make a difference. I get a lot of letters from children, since we're talking about children, and teachers encourage them to write me. I like to see that, because so often our children today end up sitting around watching television, which is sort of a one-way thing, and they're not communicating and talking and having conversations as much as they should.

The President talked about America 2000 and a national examination system. This is a voluntary system. You may be in my hometown in Merryville, TN, and you really wonder, "Well, I read all this stuff in the paper. Are our kids here learning math in the fourth grade to a world-class standard? I'd like to know." What the President wants to do is to make sure we create some standards in math, science, English, history, and geography, then a series of what he calls American achievement tests that we can use in my hometown to answer that question. Then if some kids are and some kids aren't, at least we'll have an honest answer about it and we can go to work on it. Of course, what the President is suggesting is not more tests, just different tests—tests that might give us a clearer indication. We **want** American schools with American values for our children, but we also want them to be able to learn enough and do enough—all children—to live, work, and compete with children growing up in Seoul and Taiwan and all around the world.

I was the Governor of Tennessee for 8 years, and after I had been there a while, I figured, if we just sort of get up every day and do our job, we may end up going around in circles. We have a philosopher in Tennessee named Chet Atkins who plays the guitar, and he says

something very profound: "In this life you have to be mighty careful where you aim because you are likely to get there." We talked about it with our cabinet in the State government and came up with a very short sentence about what we were trying to help our State do. Notice I didn't say "what we were going to do for our State" because that's not the way it works. That's the way some people think it works, and sometimes you read the newspapers and people say, "I'm going to do this, and I'm going to do that." That's not the way it works. What we were trying to do was use our positions in government to help people do things for themselves, community by community. And our goal for our State was to have healthy children who lived in safe and clean communities and who could go to good schools that would help them have a better life and a good job. It was that simple, and we always started with healthy children.



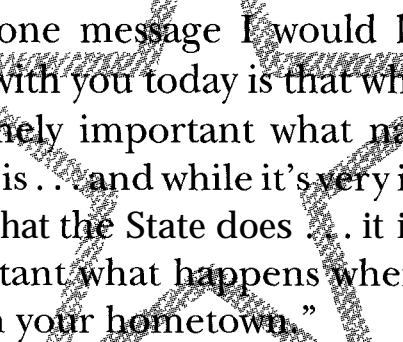
My wife was one of my educators on this. Governors really educate themselves in public, if they're smart. They don't arrive knowing everything; they really don't arrive knowing much. So, I learned a lot, and I thought that one of my roles as Governor was to help others learn as I was learning. My wife formed a Healthy Children Initiative and went to work over a period of 6 to 8 years on a number of things.

One of those things had to do with a very high infant mortality rate we had in the State and a very low level of prenatal health care. We found that for a relatively small amount of money we could take prenatal health care services, which were available in only about 30 of our 95 counties, and expand them virtually to every county. It really took placing priority on it and working on it and talking to a lot of people about it and spending some money. In the whole State budget, however, it wasn't much money. We saw results from that. I ran into individuals, women in Tennessee towns, who would come up to me and say, "I think your wife helped my baby be born healthy," because they knew that she was involved. It gave the mothers some awareness of what some of their responsibilities might be during the period of pregnancy, and it made some difference.

We found some other things that could be done. The Healthy Children Initiative revealed that many babies were being born without a pediatrician available on the first day. They also found it was entirely possible to have one available on the first day, and that it didn't necessarily cost money. The pediatricians in our State and our Healthy Children Taskforce got together and simply agreed that, if a child was born who didn't have a pediatrician identified, the hospital, doctors, and Healthy Children Initiative would designate one so that babies being born in Tennessee had a doctor. So, just those two things made a difference.

I also recall that toward the end of the time I was Governor, the head of the Healthy Children Initiative and my wife came in and said, "We need to do more in childcare." I said, "Well, the budget is already made up and we don't have any more money for this year." I was always trying to think of the practical things, you know. They said, "Oh, that's not a problem, we'll just ask the

corporations in our State to double the number of childcare spaces that they provide to their employees." Now this was 5 or 6 years ago, so it was a modest number, but we got some major corporations together, the CEOs [Chief Executive Officers], talked to them about it, and challenged them to double the number of childcare



"The one message I would like to leave with you today is that while it's extremely important what national policy is . . . and while it's very important what the State does . . . it is most important what happens where you live, in your hometown."

spaces they provided to their employees. They quadrupled the number of childcare spaces they gave to their employees, and I believe the succeeding Governor continued that initiative. I make those comments to you because many of your States, and many of you are involved in this, know of efforts to expand prenatal health care. Many of you know of efforts to identify doctors for babies from the time they are born. Many of you know of efforts to encourage employers to provide childcare opportunities for their employees; some of you might not mind doing that.

The one message I would like to leave with you today is that while it's extremely important what national policy is—that affects the spending of a lot of money—and while it's very important what the State does—that also affects the spending of a lot of money—it is most important what happens where you live, in your hometown. The truth is, the fundamental problem that

you're here about, the fundamental problem that President Bush's education initiative addresses in the end, is a matter of parents, families, and communities taking care of children and putting a priority on children as they are growing up.

It's the greatest challenge that any adult ever has—that matter of bringing a child healthy and safely into the world and helping that child grow up. I think every child is at risk from before they are born and continues that way until that person begins to have his or her own children and for some time after that. Every child is a fragile, miraculous opportunity for success and potential. The more I see of schools, communities, and this country, I think what is really happening is that we have gotten to be a very busy country, busier than ever, all of us working. It seems like our feeling of responsibility **for our** children has dropped **a few** notches, and we need to move it back up or else we'll be planting landmines in the desert all over America, and we'll never be able to find them all or to take care of them all.

I think of goal number one everyday because it's part of my job to help America 2000 communities do what the President has asked them to do: adopt those six National Education Goals; develop a strategy in their hometown to move toward those goals; and develop a report card to measure progress toward those goals and to think about creating a new, break-the-mold American school that really meets the needs of children the way they are growing up today. Then, I go to California, and the Governor reminds me that 1 out of 10 babies born in California every year is a drug baby—babies born with some poison in them. They're not all crack babies, but they are drug babies. There are 250,000 children born in California every year. That's a lot of babies, and that's an obstacle to learning. Those children have one strike against them from the day they are born in terms of their ability to grow up, live and work, and compete in a world with children from all over the world.


One of my perceptions is that more money will help, but there is a lot of Federal **money out** there, much of which could be better spent if we could find ways to organize it better. For example, Jule Sugerman came in to see us the other day. Many of you may know him. He

got busy in the 1960s and really, with some others, invented Head Start—just a little pilot program and zoom, here it goes, over the last several years. Everyone is awfully proud of Head Start. He pointed out to us in the Department of Education that there are now 27 different Federal programs that were available for children who are less than 5 or 6 years old and that the major challenge right now—while he's an advocate for more money—is spending that money wisely.

I think of Decatur, Georgia, as a wonderful example. There's a school district that, in the early 80s, had people trying to get out—parents seeking to get their children in schools in other districts. Today they are trying to get in. There are two reasons for that: One reason has to do with what goes on inside the school and the second reason has to do with what goes on in the community outside the school, both involving children. Inside, it's a tough school with high standards, teachers who are responsible for the progress of the children, and a very strict superintendent. This is a school that would have a profile for low achievement scores—it's a minority district, 90-95 percent, where most of the kids have a chance to have free lunches or free breakfasts. But in this school they have among the highest achievement scores in the school districts in the State.

What makes the difference? I think it's what goes on inside the school. The superintendent in this relatively small school district—one high school, one middle school, and a few, three or four, elementary schools—has gathered more than \$1 million of support from the community to help the children. He uses the school as the organizing point to help those children, so they don't just turn kids loose in the afternoon at 3:30 p.m. to go home to an empty house with no support. They have everyone from the Boy Scouts to the Girl Scouts to the local foundation, to the Department of Health and Human Services and Department of Education offices. They've just rounded them all up, and they've taken that money, energy, and interest, and they are fitting it with the real needs of those children. They don't interfere with the school's function of teaching and learning. I don't think we should; we shouldn't dump problems on the school that the school is not capable of

handling. But they do use the school as a center for the organization of community efforts, which helps the children become ready for school and stay ready for school as they grow up.



“Every child is a fragile, miraculous opportunity for success and potential.”

I am sure the President has told you that the Head Start increase that he's recommended is the largest one-time increase in history. The Federal budget has gone up 25 percent over the last 4 years, overall. Head Start funding from the Federal Government has gone up 127 percent. I suppose it could be more as compared to the rest of the budget, but nothing I can think of has had a higher priority than the Head Start increase. Then there's Even Start, the WIC program, and many others which I'm sure you've already discussed in the last 3 days.

The point I would like to leave with you is that when you go home, I hope you will seriously think about becoming deeply involved in creating an America 2000 community, because that will put you in the midst of what is going to be happening in America in this decade to help our children reach this goal. That's the first thing we have to do. We have to get interested, and we have to mobilize the community. They have to pay attention to mothers who have no prenatal health care, to babies who have no doctors, to children who have no one to love them or read to them, to disabled kids who need a little extra help and an opportunity to be included.

All of these take time, and we can't make progress if what we lead the Nation in is watching television. We have to get unconnected from the television and more connected with real people in our own hometowns. So if, in Derry, New Hampshire, or anywhere, they decide to respond to the President's challenge to become an America 2000 community as they have in Las Cruces, New Mexico, in Billings, Montana, in Omaha, Nebraska, in Richmond, Virginia, America will benefit. There are already 1,000 such communities; **there** will be 2,000 by the end of this year and several thousand as we move on through the 1990s. In all of those communities, goal number one is the children.

What I would hope is that while you're spending some of your time advising us how to change the Federal spending patterns, the State commissions, and the various advocacy groups, don't forget to advocate where you live, because that's where you'll make the most difference. In Decatur, when they take the children in one high school, one middle school and three elementary schools, and they mobilize everything there to help those children, they can do it, because there are that many children and there's plenty of help and they can fit it together. When we think about the whole world, sometimes it's so incomprehensible that we can't seem to find a way to make a difference. But when we think about where we live and we go outside and we spend that time with our children, which is hard to do, as so many of you do as advocates, then we can make a real difference.

The schools can be changed to fit the needs of working families and can be made more convenient. They can be made better places for children who need special help, gifted children, children who need help catching up, and children who would like to go ahead. For example, there's no reason schools should really ever be closed. That's the first conclusion reached by Derry, New Hampshire. They can open the schools in the afternoon to be convenient to working families and in the summer for kids who need special education, and everyone involved in special education knows how much a child loses between May and September. There's no need for that to happen. The schools can open up, and families that can afford it can help pay for that—it

doesn't cost much-and the Government can pay for families who can't afford it. It's just a matter of coming to the conclusion to do it.

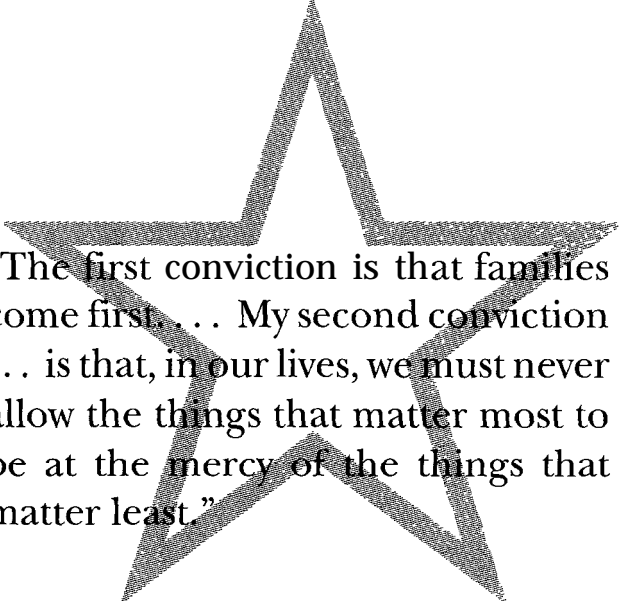
I thank you for coming, and I thank most of you for staying up so late. I've already had a glimpse at the thoughts that are behind your report just this morning. I know that the Surgeon General with her irrepressibility will make sure that all of us pay attention to what you say. We'll try to do our best here in funding and the organization of programs in ways that make a difference for you. I hope you'll keep in mind that there is a lot there to work with and that there are children who need help. Still, the most effective place to make a difference is in the family, in the community, and in the places closest to the children. Thank you very much.

Roger B. Porter, Ph.D.

Assistant to the President for Economic and Domestic Policy

It's a great pleasure for me to be with you today in the final hours of this very important Conference as you prepare to leave behind a series of findings that those of us in the Federal Government are eager and anxious to read. I salute my great friend, the Surgeon General, for hosting this conference. It is a reflection of her tireless commitment to children, to the health and well-being of our Nation, and to the strength of the American family. Dr. Novello's experience as a pediatrician has equipped her with special expertise in the subject of this conference, "Healthy Children Ready to Learn," and her eloquence as a public servant in tackling many of the most important issues of our day enables her to make a real difference.

The President earlier this week reiterated to you his commitment to the goal that all children start school ready to learn. This is a commitment that permeates his administration. The President's Education Policy Advisory Committee, which is made up of educators, business and labor leaders, and media representatives has spent much time discussing ways to enhance parental involvement in the health and education of our children.



"The first conviction is that families come first. . . . My second conviction . . . is that, in our lives, we must never allow the things that matter most to be at the mercy of the things that matter least."

I've had the privilege to be involved throughout the administration in the partnership with the Nation's Governors on education. This partnership was established in 1989 at the President's summit with Governors in Charlottesville, Virginia. Following that summit, the President and the Governors adopted six National Education Goals for the first time in our Nation's history. Those six goals provide a foundation for all of our collective efforts to revitalize our Nation's education system. They aim to ensure that our children have the opportunity to start school ready to learn and to get the kind of education that will enable those children to succeed in life.

This audience represents a marvelous commitment to that first National Education Goal-that by the year 2000 all children in America will indeed start school ready to learn. You represent millions of the Nation's parents who are the key to success in this goal. My time is short with you this morning, and I simply want to leave with you three brief convictions that I hope you will remember and carry home with you.

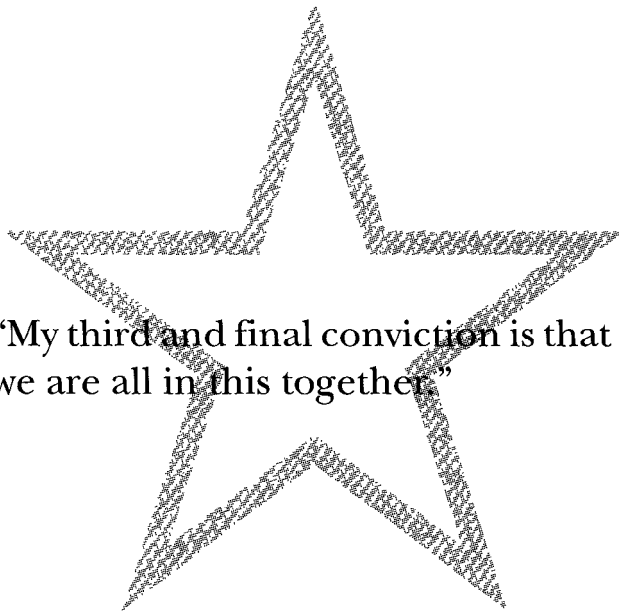
The first conviction is that families come first. As the President said to you on Monday, "In this administration, families come first." We live in a marvelous time in history and in a marvelous time in the history of the world. Never before has there been greater

opportunity and perhaps never greater challenge. The opportunities for learning, travel, and communication are almost limitless. And yet this time of great opportunity is also an enormous time of great challenge. The family, the most basic unit of our society, seems under almost daily attack. The need for concerned and loving parents and concerned and loving mentors is as great as in any time in our Nation's history. The President, sensing this great need, announced in his State of the Union Address that he was establishing a commission on America's urban families, partially in response to a remarkable meeting that he had with a group of the Nation's mayors, Republicans **and** Democrats, who came to him with a single and simple message on which they all agreed. The message was that there was not a single problem they faced in our Nation's great urban areas that did not have at its roots the disintegration of the family. They called on the President to work with them in trying to find ways to rebuild and strengthen the family. As the President said, in his administration, families come first.

My second conviction I want to leave with you is that, in our lives, we must never allow the things that matter most to be at the mercy of the things that matter least. Plato once said that 'What is honored in a country will be cultivated there.' We as a society must honor those activities that involve one generation transmitting a set of fundamental values and aspirations to the rising generation. As this Conference has so successfully articulated, these values must include good health and a commitment to learning. We must learn to reward excellence in education, not simply to eulogize athletes and entertainers. We must cultivate a culture of character in this country for, as Secretary Sullivan has reminded us frequently, the great health challenges that we face now are not communicable diseases, which 100 years ago caused our life expectancy in this country to be 45 years of age. Those have gone; we've now added 30 years of life expectancy in the last 90 years of our history. That is a remarkable event; nothing has ever been seen like it in the history of the world. The challenges we face now with respect to health are tied heavily to lifestyle-to the conscious, deliberate choices

that people make about how they are going to live their lives. We have to be about the business of helping children understand what those choices are and how to make the right ones.

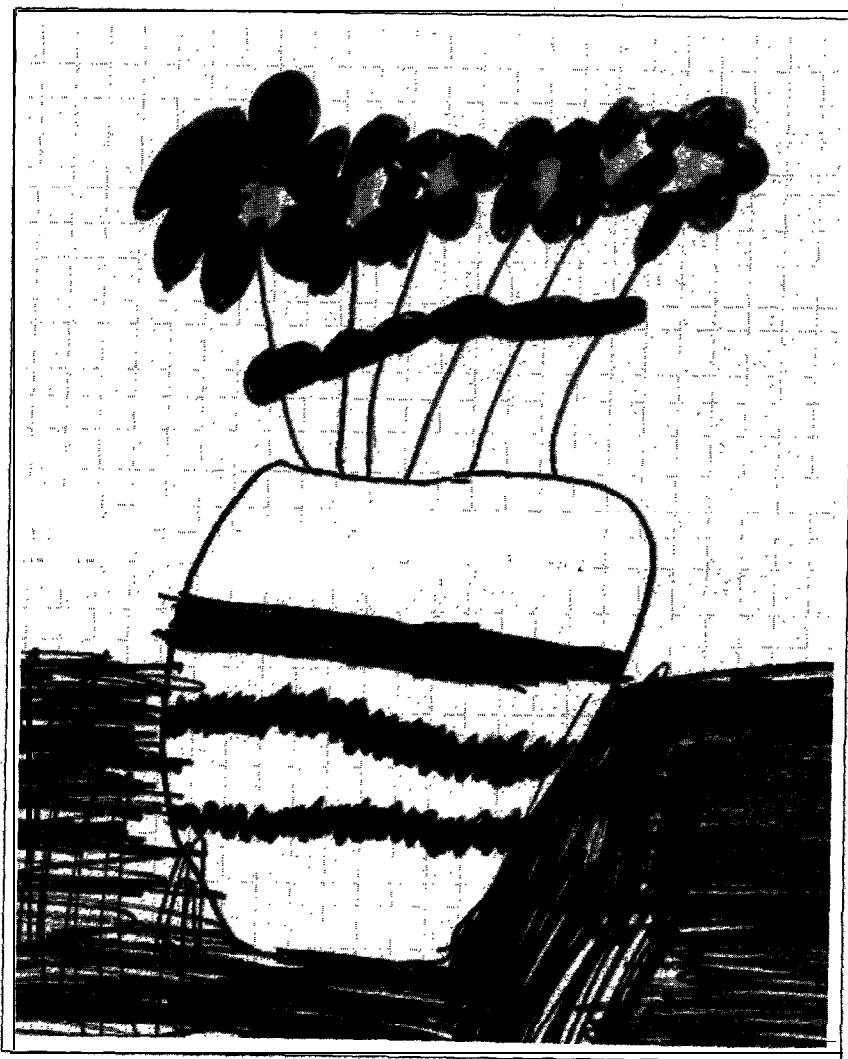
My third and final conviction is that we are all in this together. We want to cheer you on **as you** go to your homes, families, and professions after this Conference has concluded. Dedicate yourselves to communicating and practicing the critical role that we have now to pass on to the next generation the mostvaluable of treasures you can give to another person: a healthy life, committed to learning. I applaud, as many others do, your dedication and commitment, and I wish you, and all of us as a Nation, well as we undertake this important task. Thank you very much.



“My third and final conviction is that we are all in this together.”

Chapter 9

Panel Presentations



Chapter 6

Panel Presentations

While the State Parent Delegates were attending the Parent Work Groups, the General Participants attended panel presentations dealing with a number of issues related to the health and education of children. The group of more than 500 General Participants consisted of parents who were not appointed as State Parent Delegates (several of whom represented parent advocacy groups and parent networks); government officials; representatives of Federal, State, and local government health, education, and social service programs; representatives of other public (nongovernmental) programs; and representatives of private programs. Each panelist was chosen based on his or her extensive experience in the specific subject area to be presented. Two concurrent panel presentations were given in five different time periods. Summaries of the presentations follow.

Panel 1A

EARLY CHILDHOOD ISSUES THAT AFFECT SCHOOL READINESS AND HEALTH

Moderator Marilyn H. Gaston, M.D., holds the rank of Assistant Surgeon General in the Public Health Service and is currently the director of the Bureau of Health Care Delivery and Assistance at the Health Resources and Services Administration. She described four cornerstones that affect school readiness and health: adequate nutrition, proper immunization, **injury** prevention, and access to primary and preventive health care. The panel discussion focused on building preventive measures, providing quality services on time, and overcoming the barriers to adequate health care and nutrition.

Walter A. Orenstein, M.D.

*Director, Division of Immunization
National Center for Prevention Services*

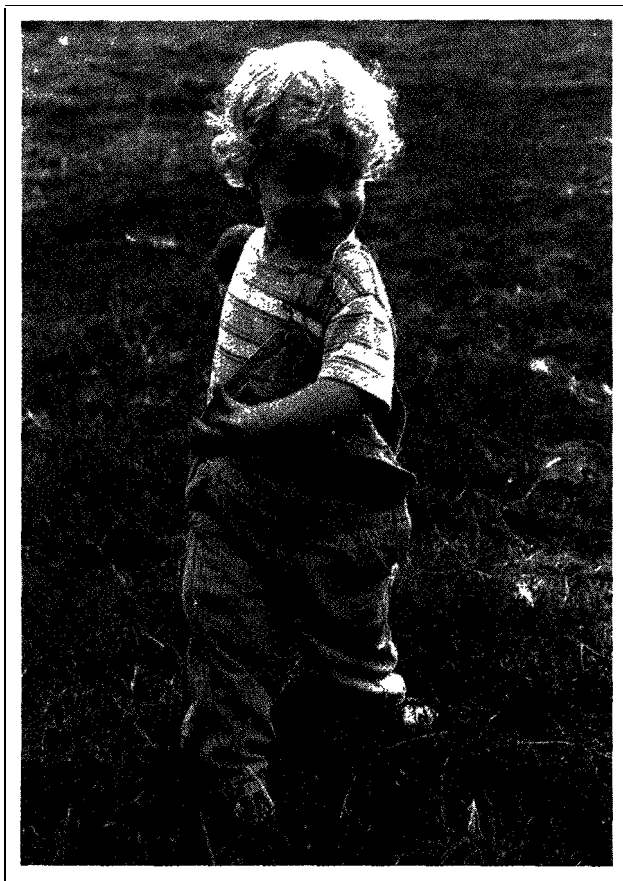
Dr. Orenstein manages the Federal Immunization Grant Program, which supports the States' immunization programs and provides nearly one-fourth of all the vaccines routinely used to prevent disease in children. He said that U.S. immunization levels are the highest in the world; State laws provide for immunization of children regardless of their socioeconomic status, race, ethnicity, etc. Orenstein emphasized that these immunization requirements provide effective protection against diseases, not only for individuals but also for communities, because high levels of immunization in a community can stop the chain of transmission.

However, Dr. Orenstein reported that recent statistics reveal some problems in our immunization programs. For example, inner cities may have large concentrations of unvaccinated people. Also, the recent measles epidemic was caused by the failure to vaccinate children at an appropriate early age. To combat the problem, Dr. Orenstein urged health professionals and other members of society to talk to each other and parents about the need to vaccinate on time and the implications of not doing so. He also talked about the importance of a community infrastructure to provide vaccinations (e.g., an adequate number of clinics available, appropriate staff, and flexible hours for vaccinations). He recommended promoting immunization through all health care contacts, such as early infancy caregivers, early childhood health care providers, and educators. He stressed the importance of figuring out the barriers to prevention. "The bottom line," he said, "is that there is no reason for people to suffer from preventable diseases."

Deborah Jones, B.S., M.S.

*Director, New Jersey State WIC Program
New Jersey State Department of Health*

Ms. Jones discussed the role of nutrition with respect to the health and well-being of children. Noting that nutrition has physiological, psychological, biochemical, and social implications, she relayed its role in



providing energy, digestion, and a host of other metabolic functions. She suggested ways to ensure adequate nutrition and talked about the recommended daily allowances of various nutrients and how they help foster proper growth and development of the very young.

Ms. Jones then focused on the symptoms and treatment of malnutrition and hunger. Both have a negative impact on learning abilities and behavior. Numerous studies of malnourished children show that they perform poorly on problemsolving and psychological, cognitive, verbal, and visual tests. Other signs of undernutrition are apathy, inattentiveness, problems interacting with others, and other learning problems. Ms. Jones noted that nutrition programs such as WIC provide several benefits, including food supplements, information on nutrition, and social services. WIC is sometimes referred to as "the gateway" to health care, immunization, Food Stamps, Medicaid, Aid to Families with Dependent Children, and Migrant Education. In the long run, WIC can save Medicaid costs for newborns

and mothers. When mothers participate in the program at the prenatal stage, both baby and mother become healthier. Ms. Jones affirmed that at-risk babies whose mothers participate in the WIC program are born heavier than those whose mothers lacked that advantage. In closing, Ms. Jones urged the eradication of malnutrition and hunger and the promotion of social services to address the needs of underserved and targeted populations. To achieve these objectives, she advised (1) educating the American population on the importance of nutrition, (2) expanding the WIC program to serve a larger portion of its eligible population, and (3) promoting programs that provide nutritious school lunches.

Modena E.H. Wilson, M.D., M.P.H.

*Associate Professor of Pediatrics
Johns Hopkins University*

According to Dr. Wilson, preventing injuries to children may be the most significant challenge to health caregivers for children. One in five children is seriously injured every year. One-half of childhood deaths are due to injury, and the number is growing. However, preventive measures have been slow to develop, noted Dr. Wilson.

Injuries to children result from a variety of incidents: accidental shootings, poisoning, falls, motor vehicle accidents (both occupant and nonoccupant), drowning, and burns from fire or other sources. The injury problem visits different populations in different ways. Statistics show that boys are more likely to have all types of injuries than girls and that children of color are at greater risk than whites. Because many types of injury require home treatment, parents need to know and apply first aid skills. However, not all parents are equipped to handle injury.

The lasting effects of injuries vary greatly, and they can be significant. Injuries may interfere with the ability to move or manipulate objects for the rest of the child's life. Head injuries interfere with physical and/or mental functioning—whether or not the child becomes completely disabled. Because injuries may affect how a child looks, they often help lower his or her self-esteem. In all of these cases, injury affects children's readiness to learn.

How do children get into situations that cause injuries? Dr. Wilson believes accidents occur in part because children live in an environment designed by and for adults. First, children's small size is a problem because they can easily slip through spaces. (Seatbelts and grocery carts, for example, are not designed for children.) Second, children lack the judgment and experience that this environment requires. For example, they ask questions such as "Is this gun a toy? Can I fly like Superman?" To combat the childhood injury problem, Dr. Wilson noted that supervision of parents cannot always be relied upon as a solution. Instead, she advocated, we need to build a better environment for children.

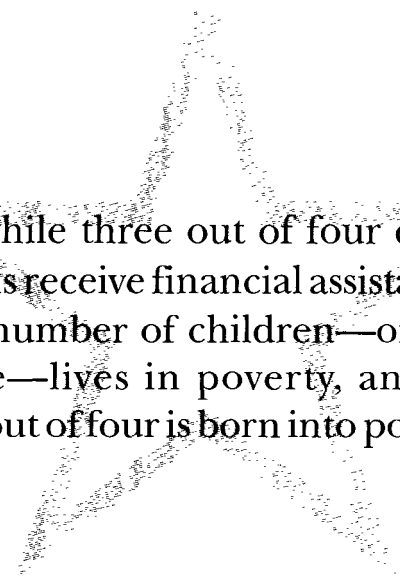
Myron Allukian, Jr., D.D.S., M.P.H.

Director, Personal Health Services

Boston Department of Health and Hospitals

Dr. Allukian spoke about the importance and the difficulty of getting primary health care and preventive health care for children. Quoting Mark Twain, he said, "Even if you're on the right track, you'll get run over if you just sit still." He urged taking an aggressive approach to solving children's health care problems, because the Nation has not emphasized that working together to produce the healthiest children is a priority. He noted that, while three out of four elderly citizens receive financial assistance, a large number of children—one out of five—lives in poverty, and one child out of four is born into poverty. Yet cash payments to needy families with children have decreased significantly. This situation broadens the gap between the haves and the have-nots and amplifies the social problems that stem from poverty—among them: (1) inadequate health care and food supply; (2) poor academic performance; (3) teenage pregnancy; and (4) widespread drug and substance abuse.

To address this situation in which many people lack health and dental insurance and an increasing amount of care is given to fewer and fewer people, Dr. Allukian offered the following guidance. First, health care priorities must be reversed so that the health care system promotes health care for everyone. To accomplish this reversal, the national budget for health care



“... while three out of four elderly citizens receive financial assistance, a large number of children—one out of five—lives in poverty, and one child out of four is born into poverty.”

must be increased. Parents, educators, health professionals, and legislators need to become more accountable. “Currently,” he warned the audience, “we are using band-aid approaches.” Head Start serves only a small portion of the people who need it. Community health centers reach only one-fifth of the children eligible for services. He noted progress in lowering infant mortality rates for the Nation; however, he said, the black population still experiences two to three times greater rates of infant mortality. Second, national leadership must promote preventive health care for every man, woman, and child. Community-based prevention services and a national health plan, including a preventive health program for kindergarten through grade 12, must be provided. The plan would include national programs in family planning to promote the concept of having children who are wanted. Third, medical schools need to be encouraged to cooperate—rather than to compete—for private sector grants. Finally, Dr. Allukian talked about the importance of sensitivity to the needs of the community and private citizens when dealing with health matters because, he said in closing, “children are 100 percent of our future.”

Panel 1B

HELPING FAMILIES GET SERVICES: SOME NEW APPROACHES

This panel, moderated by Ronald Vogel of the Department of Agriculture's Food and Nutrition Service, presented several innovative ways of eliminating the difficulties many parents encounter in trying to negotiate the bureaucratic maze that surrounds the services they need for their children. Making the system more comprehensible, more user friendly, and simpler to access was the common theme.

Juanita C. Evans, M.S.W.

*Chief, Child and Adolescent Health Branch
Department of Maternal, Infant, Child, and
Adolescent Health
Maternal and Child Health Bureau*

Ms. Evans presented the new Model Application Form whose development was mandated by the Omnibus Budget Reconciliation Act of 1989. The Model Application Form is designed to simplify the application process for individuals and families eligible to apply for any or all of the seven aid programs offered through the Maternal and Child Health Bureau. In keeping with the congressional mandate, work was completed within 1 year's time and many agencies (including the Department of Health and Human Services, the Office of the Assistant Secretary of Health, WIC, Medicaid, Head Start, and others) were represented on the interagency work group. Ms. Evans said that including representatives from the Office of the General Counsel and other reviewing bodies greatly helped the process, because their input was obtained during the development phase rather than after the fact. The Model Application Form is available for use from the Maternal and Child Health Bureau or from Governors' offices. State agencies are free to use the form in whole or in part, to adapt it as necessary, or to not use it.

Deborah Clendaniel, M.S.

*Director, Maternal and Child Health Services
Delaware Division of Public Health*

Ms. Clendaniel's presentation introduced the concept of one-stop shopping, or colocation, for health and social services delivery. This type of system has been working in Delaware for more than 20 years. Having a single point of entry into the system makes obtaining services and enrolling in appropriate programs easier for clients, thereby increasing the number of people who receive the services they and their children need. The staff of the Delaware Service Centers see themselves as a "funnel," helping to direct clients to the services they need and to which they are entitled, all during a single visit. Each center houses a variety of health and social services, including senior centers, health clinics, parole/probation offices, daycare facilities, and migrant health offices. Most are open from 7:00 a.m. until 9:00 p.m. While clients' convenience is the main concern, colocation also benefits program administrators. Information can be shared among agencies, and the certification and income verification process is greatly simplified. Referrals (e.g., for speech/language/hearing evaluations) can be made in house. Automated data management makes client information more accessible, keeps it up to date, and lets the staff members closest to the client access the data they need to make decisions. Ms. Clendaniel said that the guiding philosophy is that delivery systems must begin to accommodate, rather than merely tolerate, the needs of the population they serve.

Mary Jean Duckett

*Chief, Home and Community-Based Waiver Branch
Medicaid Bureau
Health Care Financing Administration*

Ms. Duckett explained the Targeted Case Management benefit available for some Medicaid recipients. Selecting Targeted Case Management allows Medicaid clients to choose a certified case manager to assess their needs and guide them to appropriate services and agencies. Case managers not only refer clients to Medicaid-covered agencies and providers, but also help clients interact with landlords or housing agencies, schools, and any

other areas where assistance is needed. Medicaid is a Federal agency that is State administered, and States set most of the regulations that govern who is eligible, what services are covered, and which providers are authorized to request reimbursement for services rendered. States may make Targeted Case Management available to Medicaid clients on the basis of income, certain medical or psychological conditions, geographic region, age, or other criteria as deemed appropriate. Authorized case managers can be schools, social workers, or other agencies, and case managers need not work for public agencies. States may not restrict case manager eligibility to a particular provider; rather, general qualifications must be written to allow a variety of providers to be eligible.

J. Terry Williams, RD., M.P.H.

WIC Program Director

Wyoming Department of Health

The Wyoming Health Passport, presented to the audience by Dr. Williams, uses smart card technology to record and store comprehensive medical and eligibility data for WIC clients in a format that is portable, inexpensive, easy to update, and confidential. The passport itself, which looks like a credit card, is a 16 kilobyte microcomputer. The cards cost about \$10 each and have an estimated life of 5 years. A card's memory capacity can be doubled for about \$0.40. Because WIC information takes up only about one-third of the card's memory, the remaining memory is open for other agencies to use. A client who visits a service provider presents his or her card; the client's history is available to the provider, and the card is automatically updated each time services are rendered. Clients control access to the information through the use of PINs. Clients can obtain paper copies of their entire record at WIC offices. Dr. Williams said that the Health Passport has been especially valuable in sparsely populated Wyoming, because it eliminates both the delay and the cost of mailing, telephoning, or faxing information among agencies. Other States that are preparing to pilot similar programs are Montana, North Dakota, and Idaho.

Clara L. French

Food Program Specialist

Supplemental Food Programs Division

Food and Nutrition Service

U.S. Department of Agriculture

Ms. French closed the session with a discussion of privacy and confidentiality of client information. Although integrating services and sharing data have benefits, such exchanges may sometimes threaten patient confidentiality. Many Federal and State regulations govern the exchange or disclosure of personal information. Special regulations apply to certain sensitive information, such as program records concerning substance abuse, AIDS status, sexual history, and actual or suspected child abuse. In integrated data systems, confidentiality may be maintained by the use of passwords, read-only screens, exclusive or restricted access files, and other methods. In searching for the appropriate balance between data sharing and client privacy, Ms. French asserted, administrators should solicit clients' opinions about what information may be shared and what information may not. Administrators must review and become familiar with the requirements of all applicable legislative, regulatory, or policy restrictions on the release of information. Finally, Ms. French urged continued cooperation among agencies and programs as they work to balance these two important concerns.

Panel 2A

HEALTHY CHILDREN READY TO LEARN: WHAT ARE THE ROLES OF PARENTS, EDUCATORS, HEALTH PROFESSIONALS, AND THE COMMUNITY?

The theme of this panel, moderated by Josie Thomas, Project Coordinator for the Family and Community Networking Project at the Association for the Care of Children's Health, was cooperation among parents, educators, health professionals, and the community in raising healthy children. Each speaker stressed the need for true collaboration, interdependent partnerships, and empowerment.

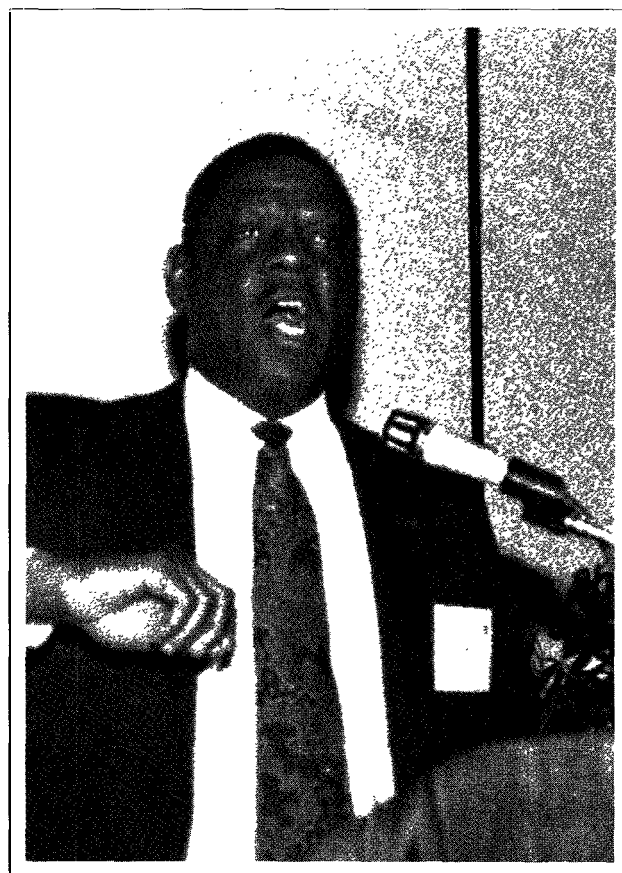
Rosalie Streett*Executive Director**Parent Action*

Ms. Streett urged the audience to put family issues at the top of the national agenda and to improve the quality of life for American families. Highlighting the pivotal role of parents in meeting these goals, she said people should turn to parents first when looking for information pertaining to children's well-being. "The only people who can make a change for parents," she said, "are parents." She cited adoption statistics to illustrate how rapidly the world has changed. Fifteen years ago, the process to adopt a child took an average of only 9 months. Now, the situation has reversed, with only 1 of 85 teenagers presenting her baby for adoption, thus creating a shortage of adoptable babies and long waiting lists for prospective adoptive parents. However, Ms. Streett emphasized that, in the face of a changing society, the needs of children and the need for strong families have not changed and never will change. Unfortunately, today's demands on people's lives may cause them to forget about the support that children need. Although the support children need is common knowledge, not everyone recognizes that parents are the largest untapped political constituency. Ms. Streett offered the following guidance. (1) Ensure that every political candidate-local, State, and national-supports the needs of parents. (2) Encourage parents to voice their needs. For example, children's needs can be supported by creating a better workplace. Some offices, she said, are leading in this direction by allowing children to come to work with their parent when the childcare provider is sick. Noting that the United States is possibly the only western country that does not have a family and medical leave policy, Streett told the group that it's time to get motivated. (3) Encourage children to be creative and interactive. She directed parents to turn off the video games and television. In closing, she urged the audience not to "take the easy way out because we're tired, because none of us are as tired as our grandmothers were."

Willie Epps, Ph.D.*Director, Head Start Program**Southern Illinois University at Edwardsville*

Dr. Epps spoke about the integral role of educators in the partnership with parents and families, health professionals, and community resource people. Collaboration, he said, enables educators to interact effectively with individuals, families, groups, and communities to enhance awareness of problems, promote appropriate action, and advocate solutions. He talked about the need to establish goals, which he defined as simply dreams with a timeframe, such as President Bush's goals for the year 2000. The educator's goals must maximize the physical, emotional, and social well-being of children. A compromise in any of these areas might affect children's ability and willingness to learn. Realization of goals, said Dr. Epps, requires educators to use knowledge and skills effectively in these three roles: (1) assessor, (2) advocate, and (3) promoter

HEALTHY CHILDREN - Ready to Learn



Dr. Epps elaborated that, although formal mechanisms such as screening activities and programs help educators assess children's needs, these mechanisms shouldn't replace the daily monitoring of children's behavior and actions. By observing behavior, attitude, and/or symptoms in daily interaction with children, educators can begin to understand the physical, emotional, and social risk factors that have a negative impact on children's health. They then can address actual or potential needs by communicating their knowledge about children's patterns of growth and development to other members of the partnership-families, community resource people, health professionals-to reinforce behavior (if healthy) or intervene (if unhealthy). In the role of assessor, educators must negotiate, consult, and refer. They must work with outside health professionals to gain knowledge and skills so that families and schools can replace unhealthy lifestyles with healthy ones.

As advocates, educators influence the way the community views and responds to the goal of making children healthy. In this role also, Dr. Epps noted that strong collaboration with other partners-legislators, civic leaders, corporate officers, and community leaders-is crucial. For example, noting that Head Start can

be replicated anywhere and that Head Start makes children ready to learn, Dr. Epps stressed the fact that public schools are not yet ready to receive Head Start graduates. Public schools need to collaborate with the local Head Start programs. The message needs to ring clear that (1) society is in danger when children's health is at stake, (2) children's health and learning go hand in hand, and (3) proper resources must be allocated to ensure the health of children.

As positive role models, educators must promote a healthy lifestyle by showing nutritious eating patterns, participating in exercise and fitness, practicing stress management techniques, and eliminating substance abuse. Finally, educators must promote comprehensive school-based health programs as feasible and cost-effective. In closing, Dr. Epps reminded the audience that healthy children are the product of instituted and sustained change. "Only through health," he said, "can children learn."

Robert G. Harmon, M.D., M.P.H.

Administrator, Health Resources and Services

Administration

U.S. Public Health Service

It is important to get children healthy and ready to learn each year, in 2nd grade as well as 12th grade, began Dr. Harmon. His presentation focused on the role of health care professionals in making children healthy, the problems they face, and characteristics of successful collaborations. He noted the multitude of problems that concern health care professionals: low birth weights, infant mortality rates, immunization, and environmental contaminants. To address these problems, he said, communities need partnerships of all kinds: between the public and private sectors; between various professionals such as psychiatrists, social service workers, and family physicians, etc.; and between parents and all others in the partnership. The family environment is the most significant factor in providing for children's health, said Mr. Harmon, because, "while social service systems fluctuate, the family is constant." The family profits from successful collaboration. Among the criteria for evaluating

"The message needs to ring clear that (1) society is in danger when children's health is at stake, (2) children's health and learning go hand in hand, and (3) proper resources must be allocated to ensure the health of children."

“The family environment is the most significant factor in providing for children’s health ... because, ‘while social service systems fluctuate, the family is constant.’”

programs is the ability of health professionals to (1) understand the development needs of infants, children, teenagers, and families, (2) provide family-centered care, (3) provide emotional support to families, (4) understand and appreciate that families have different methods of coping, (5) access a delivery system that is responsive to parents, (6) be culturally competent, (7) understand and honor racial, ethnic, and cultural differences among families, and (8) respect beliefs, attitudes, and talents of family members.

Charles P. LaVallee

Executive Director

Caring Program for Children

Western Pennsylvania Caring Foundation, Inc.

The Caring Program for Children is a Blue Cross and Blue Shield program that acts in partnership with the community to provide free primary health care to children living in poverty. The program operates on the premise that children won’t be ready to learn if they are not healthy, and the program’s overall goal is to empower parents. Therefore, a key feature of this program is that each participant receives a medical card so that no one knows he or she is in need, and confidentiality and family dignity is thereby protected. The program works because the burden is shared

between the physician who provides care in the hospital and Blue Cross and Blue Shield, which matches expenses. Empowerment of people in this way and building of partnerships are key to the success of this type of program.

One of the problems society faces, said Mr. LaVallee, relates to the “knowledge gap” about the large number of people who lack health care insurance. A strategy for combatting the problem of the uninsured is to promote community fundraising programs that keep funds in that particular community. The strategy works with the help of community leaders and mobilization of power bases, because people are attracted to projects designed to keep money at home. Mr. LaVallee stressed the need to form partnerships with hospitals, legislative staff, and community leaders, among others. He also emphasized the need to work with both the media and members of these partnerships to find people in need in the community. He cited some examples. In one case, WIC workers, school nurses, and hospitals discovered people in need. In another case, the media used an identifiable figure—television’s Mr. Rogers—to identify thousands of needy children.

Poverty health care needs are an important priority. To underscore this importance, Mr. LaVallee posed a situation in which chronically ill children of deceased parents lose their eligibility for medical assistance once their social security income runs out. Mr. LaVallee recommended dramatizing such situations through the media.

Panel 2B

SPECIAL ISSUES THAT IMPACT CHILDREN AND FAMILIES: SUBSTANCE ABUSE, HIV, AND VIOLENCE

Moderator Bill Modzeleski of the Department of Education's Office of Drug Planning and Outreach called this panel one of the most important at the Conference. He stressed the relevance of the issues that would be discussed by the panelists, noting that these issues will touch the overwhelming majority of American children and adolescents before they graduate from high school. Substance (drug, alcohol, and tobacco) abuse, HIV and AIDS, and violence affect our families and communities without regard to race, region, or income level.

Beverly Coleman-Miller, M.D.

President

The BCM Group, Inc.

Dr. Coleman-Miller spoke about the impact of violence on children, which she has observed in more than 25 years' experience in the medical field. She cited the horrendous statistics for deaths, shootings, and stabbings, then pointed out that these figures account only for reported incidents. The growing acceptance of violence in the streets as a part of life is, according to Dr. Coleman-Miller, the single biggest problem that must be overcome in putting an end to violence. "The United States understands that children who witness violence are different from children who don't," she said, citing the special educational and counseling programs that were launched for children during last year's Gulf War. No such programs exist for children who witness street violence on a daily basis. Dr. Coleman-Miller expressed her belief that the time for studying the effects of violence on children is past; now we must work to eliminate violence. She reminded the audience that violence affects all of us. Children who witness violence at an early age grow up believing that violence is an acceptable way to deal with conflict, and the cycle

is repeated in the next generation. The strain on the medical system also affects everyone. When hospitals and trauma centers are forced to fold under the pressure of providing free medical care to indigent patients who have been shot or stabbed, the result is fewer hospitals and trauma centers available to all. Dr. Coleman-Miller closed the session with an invitation to her workshop session, where she would discuss intervention strategies.

Dr. Wendy Baldwin

Deputy Director

National Institute of Child Health and Human Development

Dr. Baldwin discussed the social effects of pediatric and adolescent AIDS cases. Dr. Baldwin emphasized that in pediatric AIDS cases, we must consider families with AIDS, not just children with AIDS. More than 3,400 children in the United States are known to have AIDS, and because full-blown AIDS is the end stage of the disease, the number of children who are HIV-infected is assumed to be much larger. Current estimates place the number of infected children between 10,000 and 20,000. AIDS is the ninth leading cause of death for children in the general population and the sixth leading cause of death for African-American children. AIDS affects minorities and the poor

"AIDS is the ninth leading cause of death for children in the general population and the sixth leading cause of death for African-American children."

disproportionately, often striking individuals and families least equipped to deal with the resulting pressures.

Children contract AIDS in one of two ways: they are born to an infected mother or they receive a contaminated blood transfusion. In most cases, at least one parent already has the disease. Often, the family has a history of substance abuse, and many children with AIDS are members of unstable or single-parent families. Poverty is another problem that frequently affects AIDS families. Many HIV-positive children are wards of the State and are therefore denied access to the state-of-the-art treatments that are available only in clinical trials.

The stigma attached to AIDS because of its routes of transmission (intravenous drug use or unprotected intercourse) can lead to grave consequences for children who are diagnosed with the disease. In some cases, parents have hidden the child's condition and have refused to seek medical treatment for the child. An HIV-positive diagnosis has in some cases led parents to abandon their children. When children become infected through contaminated blood transfusions, the stigma, emotional pain, and financial strain of this new disease often compound the worries of the medical condition that required the transfusion in the first place.

Adolescents constitute a significant risk group, especially those who lack the supervision and guidance that a strong family provides. Unprotected sex and drug use remain the two biggest risks for HIV transmission among teenagers. Dr. Baldwin said that, while parenting skills did not require extra work in quieter times, parents must devote added attention and effort to rearing children in this turbulent era. "Families are the basic socializing unit for children," she said, as she underscored the importance of teaching children self-esteem and discipline early in life.

Millie Waterman

Interim Chairman

National Parent/Teacher Association (PTA) Health and Welfare Commission

Ms. Waterman presented the PTA's approach to addressing the critical problems of substance abuse, AIDS, and violence. At the heart of all its policies is the PTA's 95-year-

old tradition of support for parent involvement. The National PTA is working to achieve three major goals in conjunction with the President's six National Education Goals: (1) to design and implement comprehensive parent involvement programs in schools across the country, (2) to identify and eliminate the risks to children, and (3) to use the schools as a delivery point for counseling, nutrition, and health programs.

On the topic of substance abuse, PTA advocates a "no use" policy designed to eliminate the mixed messages children receive about drugs, alcohol, and tobacco. Although the use of illicit drugs (such as cocaine and marijuana) has declined over the past decade, the use of alcohol and tobacco has increased. To be successful, Ms. Waterman said, drug use prevention programs must discourage the use of all drugs and must be supported by the entire community. Not only children but also parents must be educated about drug use. PTA is the recipient of a grant from General Telephone and Electronics, Inc. (GTE), for a program called "Common Sense," which targets children between the ages of 8 and 12. This program is based on three components: (1) building strong bonds between children and families, (2) setting limits and rules for children, and (3) serving as good role models for children. PTA also calls for an end to

"At the heart of all its policies is the PTA's 95-year-old tradition of support for parent involvement."

television advertising for beer; this advertising is most often aired during sporting events, which are watched by thousands of children who get the impression that, in Ms. Waterman's words, "beer time is party time."

On the subject of AIDS, PTA has begun a **program** called "AIDS Education in the Home and at School" with a grant from the CDC. PTA urges all boards of education to establish policies on the school placement of children with AIDS and on AIDS education in health and hygiene classes. PTA advocates sexual abstinence as the best way to prevent the spread of AIDS among the teenage population.

PTA also recognizes the many forms violence takes in our society. Corporal punishment, or beating children as a means of discipline, is legal in 28 States. The National PTA promotes banning corporal punishment across the country. Television violence is another area of concern. The National PTA also works to reduce the violence that gangs and child abuse inflict upon our children.

Mark L. Rosenberg, M.D., M.P.P.

*Director, Division of Injury Control
National Center for Environmental Health and
Injury Control
Centers for Disease Control*

This presentation on the public health approach to violence prevention closed the session. Like Dr. Coleman-Miller, the opening speaker, Dr. Rosenberg stressed that the time for action has come. The solution to violence in America isn't buying guns, installing home alarm systems, or putting metal detectors in the schools; rather, it is preventing violence in the first place.

Although the popular conception of CDC has to do with diseases such as AIDS and toxic shock syndrome, CDC's prevention philosophy is no less applicable to violence. According to Dr. Rosenberg, "accident" is a word that has been removed from the CDC vocabulary because it implies that injury is unavoidable. On the contrary, he said, violence is preventable using the same steps that researchers follow in epidemiological (disease control) studies. First, the reports of violence and intentional injuries are studied to determine recurrent patterns. Next, researchers work to design possible

interventions that would prevent such incidents. These interventions are then tested to determine which are most effective.

Dr. Rosenberg emphasized the prevention aspect of CDC's approach. Unlike police officers and other law enforcement professionals, public health professionals can get involved before the harm is done. Public health officials also have access to a broader range of incidents, because unlike police, they can work on cases where no criminal activity is involved. As part of CDC's prevention efforts, Director Bill Roper recently announced his intent to begin a National Center for Violence and Injury Prevention at CDC.

Panel 3A

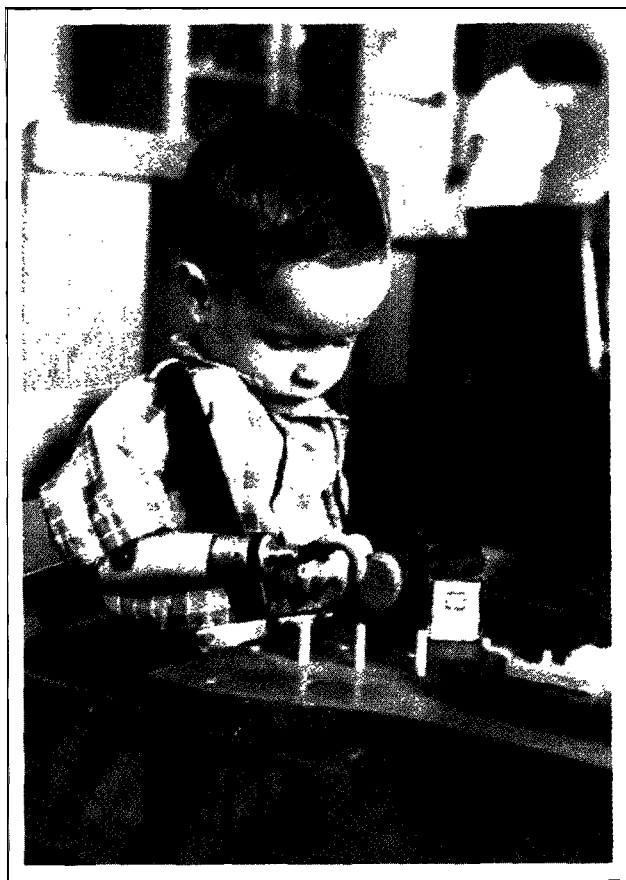
DISABILITIES

Moderator Vernon N. Houck, M.D., Director of the National Center for Environmental Health and Injury Control at the Centers for Disease Control, began this discussion by contrasting recent progress in eliminating diseases, such as polio paralysis, rubella, and cerebral palsy, with the need to reduce the causes of developmental disabilities in children. Prevention of the diseases was successful, he stated, because the cause in each case was identified. However, learning disabilities such as those related to childhood lead exposure are not yet preventable because lead poisoning and its sources often cannot be pinpointed. In their discussion of lead poisoning, mental retardation, fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE), Dr. Houck and the panel speakers delivered a common message: although it is costly to remove pollutants and take preventive measures to combat other disabilities, "the cost of doing nothing is far more than the cost of finding interventions and applying them." The speakers emphasized education and prevention, wherever possible. When prevention is not possible, quick intervention and diagnosis are needed. Equally important is research to determine the causes of disabilities if they are not completely understood.

Sue Binder, M.D.

*Chief, Lead Poisoning Prevention Branch
Centers for Disease Control*

According to Dr. Binder, childhood lead poisoning is an ancient problem. The Romans discovered the sweetness of lead salts and used them in alcohol. Today, water and soil have more lead in them than we think, and lead is still found in paint. As a result, children ingest lead as part of their normal hand-to-mouth activity. Although lead-based paint was federally banned in the 1920s and 1930s, it is still used from time to time. In the 1940s, several cases of lead poisoning manifested symptoms like inflammation of the brain, inability to walk and talk, and—in the worse cases—death. The Byers and Lord study followed 20 6- to 11-year-olds with problems suspected to be caused by lead poisoning. The researchers found that the children's intelligence quotient (IQ) was average, but they did poorly in school. The children appeared to be smart, but they did not learn. In the 1970s, the Needleman study examined lead exposure in



children who did not display symptoms by measuring lead levels in their teeth. The findings revealed a positive correlation between high lead levels, in teeth and teachers' evaluation of distractibility and other academic performance characteristics. Children with high lead levels had lower IQs (by 4 points) and did not perform as well as those with lower lead levels. The Needleman study followed these children for 11 years (through high school). The followup findings showed that, although these children displayed basically normal IQs, they performed below normal and had high dropout rates and absenteeism.

The tragedy is that these problems of lead exposure are preventable. However, according to Dr. Binder, "Until the 1970s, people were not concerned with lead exposure unless they displayed symptoms." At that time, 40 micrograms of lead per deciliter was considered to be a problem. In 1991, the Surgeon General considered 10 micrograms per deciliter to be a problem. "The bad news," said Dr. Binder, "is that we worry about lead levels that are lower and lower, but the good news is that we are finding the average blood lead level to be dramatically declining." The reason for this decline can be attributed to lower lead in gasoline and stricter laws by the Environmental Protection Agency that result in reduced lead levels in blood. We have reduced these environmental sources.

However, the major sources of lead still are lead-based paint, paint-contaminated dust, and debris from window wells that children ingest in normal hand-to-mouth activity. Older homes that have undergone renovation are a particular problem. The Department of Housing and Urban Development estimated that, in 1980, 74 percent of homes still contained some lead-based paints. In November 1990, Herbert Needleman spearheaded a plan with a program agenda that called for an increase in the number of prevention activities and programs, an increase in the abatement of paints and lead poisoning, and an increase in the surveillance of elevated blood levels in children. This agenda has resulted in increased funding dollars and increased efforts to promote partnerships in the private sector and foundation support, among others.

Craig T. Ramey, Ph.D.

Director

Civitan International Research Center

Dr. Ramey described the “rapidly changing landscape” for children with disabilities, particularly mental retardation, as society stands on the threshold to mount new research for programs to treat and prevent these disabilities. Mental retardation, he said, represents 75 percent of all disabilities and is predictable; it is not randomly distributed. The poor are at a much greater risk for mental retardation than other populations. Perhaps 25 percent of individuals that fall below the poverty line are at an elevated risk for mental retardation that lasts over more than one generation. Mothers with an IQ lower than 70 are also at greater risk of having mentally retarded children.

Mental retardation is caused by factors such as poor health care and systemic mild insults. Seventy-five percent of mental retardation fall in the mid-range (IQ of 55 to 70). “The notion that mental retardation is a permanent characteristic of a person,” said Ramey, “has been challenged by longitudinal and ethnographic research. . . . Treatment of mild mental retardation has been synonymous with education and the provision of rehabilitative environments.”

Recent research in mental retardation has shown that low-birthweight and premature infants are born into a “double jeopardy” situation because they were born not only with low birth weight and premature, but in disproportionate percentages to disadvantaged families. These children did relatively well when they received intensive home treatment with individual care and a vocational curriculum with a very good teacher-to-child ratio. This treatment and development program, which is affiliated with several universities, was implemented in eight program sites across the country. In most cases, significant improvements occurred when key components were followed: intervention, followup, surveillance, referrals, and home visits. In this study, followup was more extensive than in many other similar intervention studies. Across the board, those in the more intensive intervention group were at an advantage. The frequency of mental retardation decreased in direct proportion to the amount of

intervention received. The followup of children (through age 12) showed high risk children had an IQ of below 85 (borderline intelligence). For those mentally retarded children who received early intervention, only 28 percent repeated at least one grade by age 12. Without early intervention, 55 percent repeated at least one grade by age 12.

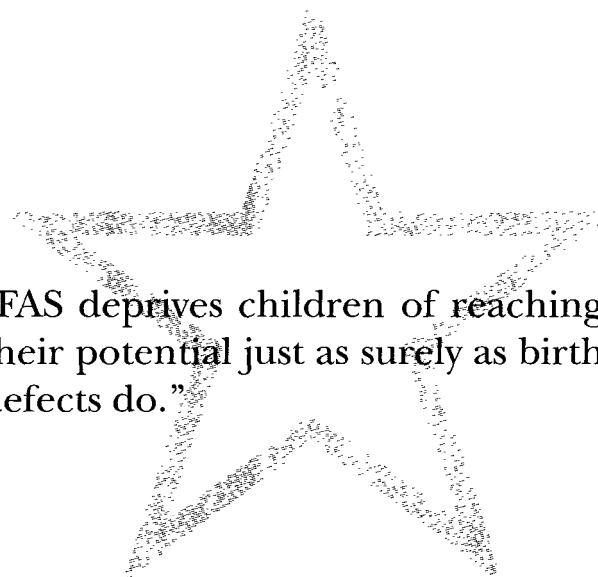
Ann Streissguth, Ph.D.

Director, Fetal Alcohol and Drug Unit and Pregnancy and Health Studies

University of Washington

Children afflicted with FAE and FAS are unable to reach their full potential due to prenatal alcohol exposure, according to Dr. Streissguth. These youngsters have normal intelligence but can't “get it together.” They often suffer from distractibility, attention deficit disorder, and the lack of ability to focus on important issues. However, FAS, she emphasized, is totally preventable. “It's one thing to prepare children for school,” she said, “but it's a big responsibility to ensure that each child begins life in an alcohol-free environment.”

FAS deprives children of reaching their potential just as surely as birth defects do. However, birth defects are observable. For example, children exposed to thalidomide have noticeable physical defects. FAS, by



“FAS deprives children of reaching their potential just as surely as birth defects do.”

contrast, is a hidden disability. Because ethanol crosses the placenta freely, in minutes the blood level of the fetus is the same as that of the mother. Symptoms of FAS include (1) prenatal and postnatal growth deficiency, (2) a pattern of malformation in terms of facial features (large distance between eyes, thin upper lip, and flat midface) and brain composition, and (3) central nervous system dysfunction. The misconception is that all children with FAS are mentally retarded. In reality, only 50 percent are retarded; many with FAS are borderline intelligent. However, all children with FAS are dysfunctional. "IQ is not the factor that determines how well a person functions," affirmed Dr. Streissguth, "underlying brain damage is."

Dr. Streissguth stated that victims of FAS are at high risk (many are involved in crime), and the long-term consequences of the problem need to be understood. She brought attention to the severity and magnitude of FAS and FAE and stressed the need for education and early intervention. She has received many letters from parents—one of which she read aloud—stating, in effect, that our system fails these children. Dr. Streissguth advocated (1) public education, (2) professional training, and (3) professional services. People need education about the risks associated with social drinking during pregnancy (i.e., there is no known safe level of alcohol exposure during pregnancy). Specifically, Streissguth recommended (1) improved diagnosis of FAS and FAE and (2) design of special programs for children with these problems so that they can find productive places in society and are not failed by society. She acknowledged that many people simply don't recognize the difference between brain damage (an effect of FAS and FAE) and retardation. She emphasized the need to diagnose young children, adolescents, and young adults. Without a successful diagnosis, she said, these children remain in an environment that offers no help for them.

Panel 3B

EXPLORING COMPREHENSIVE HEALTH AND EDUCATION MODELS FOR YOUNG CHILDREN

Moderator Mary Brecht Carpenter of the Commission to Prevent Infant Mortality introduced the panel members. The two speakers on this panel presented concrete recommendations for innovative ways to improve health, education, and social services delivery for young children.

Edward Zigler, Ph.D.

*Director, Bush Center in Child Development and Policy Study
Yale University*

Dr. Zigler, a self-described "Congressional gadfly," presented his views on the future of childcare in this country and outlined his plan for the School of the Twenty-First Century.

As long ago as 1970, Congress recognized the need for a national childcare system. In 1971, Congress passed legislation that would have mandated a national network of childcare centers, but the bill was vetoed by then president Nixon. Dr. Zigler stressed that childcare is now an even more important national priority due to two particular demographic shifts: (1) the dramatic

"We cannot treat children the way we are currently treating them in the childcare setting in America and expect this to be a great nation."

increase in the number of mothers working outside the home and (2) the increase in the number of single-parent families. Today, 65 percent of mothers with school age children work outside the home. The figure for mothers of preschool children is 60 percent. Among women with children less than 1 year old, 54 percent work outside the home. Moreover, the Department of Labor estimates that, by the year 2010, labor shortages will draw even more mothers into the work force. Today more than 25 percent of all American children and 50 percent of black children grow up in single-parent families.

Research on the impact of daycare on children, Dr. Zigler noted, has shown that good daycare is good for children and bad daycare is bad for children. We know how to provide good care, but we don't want to pay what it costs. "The general state of childcare as experienced by children in this country is abysmal," he stated. "This country is getting what it pays for." The average annual turnover in childcare facilities is about 40 percent. As many as 90 percent of daycare centers in the U.S. are completely unregulated. No national standards exist, and there is wide variation among States. Even where standards exist, they are too lax to be of much use. Based on studies recently completed in California, Dr. Zigler estimated that about one-third of centers in this country are so poorly managed and the quality of care is so low that children are being "seriously compromised." He went on to say, "We cannot treat children the way we are currently treating them in the childcare setting in America and expect this to be a great nation."

Although the 1990 Childcare Block Grant has been hailed by many as a victory for childcare reform, Dr. Zigler expressed doubt that it will have any significant positive effect. Seventy-five percent of the funds allocated to the Block Grant are earmarked for poor or nearly poor families. The middle class, which is equally in need of good childcare, will see almost no benefit, and Dr. Zigler expressed his fear that this situation may lead to backlash against the grant and against childcare reforms in general. He stressed the relationship of good daycare to achieving the President's six National Education Goals. "Five lousy years of childcare will



guarantee that they [children] will show up at school not ready to learn."

In Dr. Zigler's opinion, the system as it currently exists does not work and cannot be made to work. Instead of trying to retrofit the current system, he proposes a whole new system that he calls the School of the Twenty-First Century. The program, as Dr. Zigler envisions it, will incorporate the following key features:

- ★ Two systems will exist: first, the formal, 9-month, 8:00 am to 3:00 pm school, and second, the 12-month, 7:00 am to 9:00 pm school.
- ★ Children will enter the system at the age of three for full-day, developmentally appropriate school. In communities that already have Head Start programs, Head Start could simply be blended into the system; parents with earnings above the poverty line will pay an enrollment fee.
- ★ Before- and after-school childcare will be provided for children aged 6 to 12.

- ★ Each family will be assigned a home visitor who will conduct developmental screening, offer support to parents, etc.
- ★ All family daycare programs will be tied in to the school, which will offer support and periodic training sessions for childcare providers.
- ★ The school will contain a comprehensive information and referral system that can direct families to appropriate health and social services agencies (such as immunization clinics or night care providers).

Successful pilot programs to build Schools of the Twenty-First Century already exist in several States, including Missouri, Connecticut, Colorado, Wyoming, Texas, Kansas, Idaho, Arkansas, and Mississippi.

Another proposal Dr. Zigler is attempting to present to Congress is the “Children’s Allowance for America.” This plan would allow a new parent to withdraw up to \$5,000 from his or her own Social Security account to allow the parent to stay home or to help pay for good childcare.

Nancy Van Doren

*President, Travelers Companies Foundation
Director, National and Community Affairs Division
The Travelers Companies*

Ms. Van Doren spoke on behalf of the Travelers Companies Foundation about the role that businesses and private organizations can play in securing good care for children and pregnant women. The Travelers are headquartered in Hartford, Connecticut—one of the poorest cities in the country, located in one of the richest states. Disproportionately large numbers of children in Hartford are born to teenage mothers, are underimmunized, and have asthma, attention deficit disorders, or learning disabilities. All of these conditions are usually preventable. As one of the organization’s social responsibility commitments, the Travelers are working to improve the health of children and the prenatal care of mothers in the greater Hartford area.

When a new children’s hospital was proposed for Hartford, the Travelers commissioned an independent

analyst to conduct an evaluation of Hartford’s health **care** delivery needs. The consultant found that, while Hartford would indeed benefit from having another hospital, it was even more important to increase availability of primary and preventive health care for children and expectant mothers. Ms. Van Doren said that it has been a challenge to persuade contributors and decisionmakers to redirect their limited resources from “glamorous,” high-visibility projects such as new hospitals to more mundane (but effective) applications such as prenatal and perinatal health clinics for low-income mothers.

Ms. Van Doren said that she is motivated in her efforts by a mixture of rage and shame that people in her community are unable to have even their most basic needs met. She urged the audience to let their rage and shame move them to act and to search for opportunities to push for the redirection of resources to the places where they can do the most good. Hartford has been successful so far in its drive to reallocate resources from prisons to schools, and from neonatal intensive care units to preventive care. Ms. Van Doren emphasized the importance of preventing health crises rather than remedying them.

Panel 4A

CHILDREN WITH SPECIAL HEALTH CARE NEEDS: LESSONS LEARNED

This panel offered valuable insights about setting up systems that address the problems of children with special health care needs. The speakers offer three perspectives—all key to successful programs: (1) parent empowerment, (2) program-level development, and (3) State-level involvement. The panel was moderated by Rear Admiral Julia R. Plotnick, M.P.H., R.N.C., who holds the rank of Assistant Surgeon General and is the Associate Director, Division of Services for Children with Special Health Care Needs, at the Maternal and Child Health Bureau.

Diana Robinson

Parent/Child Advocate

Center for Successful Child Development

Ms. Robinson serves as a parent/child advocate at the Robert Taylor Community-known to be the largest public housing division in the United States-where she has resided for more than 20 years. Her video presentation highlighted the daily struggles of a community with highly concentrated and severe poverty and its associated problems: extreme overcrowding, extremely high infant mortality and morbidity rates, high incidents of low birth weight, high percentage of teenage mothers, and high rates of violence. The community is further crippled by threatened family unity; psychological and physical absence of fathers; anger, depression, and despair; and social isolation.

Ms. Robinson's determination to help herself and fellow community members led to her advocacy work on the Beethoven Project at the Center for Successful Child Development. The Center provides community-based services that address the health, education, and social needs of the community. The Center's philosophy is based on two beliefs: that each individual has the ability to achieve and be independent and in control of his or her life, and that strong family relationships are important. Services are tailored to the needs of individual families, in a type of holistic service plan.

Instead of focusing on the barriers to improving community life, said Ms. Robinson, the Center builds on community strengths to deal with the problems. From her experience at the Center, Ms. Robinson shared two basic problems and approaches to solving them. (1) Economic entrapment and isolation leads to a month-to-month struggle to meet basic needs. To address this problem, the Center offers ongoing employment training, counseling, and referrals. The Center also provides other tools to make life easier and help people to help themselves. Project staff are empathetic rather than sympathetic, and support groups abound. (2) Educational opportunity is lacking in the community. Project staff help parents to become better persons as well as better parents. The Center recognizes that parents who feel powerless and/or inadequate as parents don't read to children. Staff

members stress the importance of reading to their children and other approaches parents can use to foster school success. The staff encourage strong parent-child relationships and emphasize taking pride in the child's academic achievement.

Finally, parents are taught to become accountable and take an active role in their children's lives and in their community. Said Ms. Robinson, "Healthy parents ready to learn will provide us with healthy children ready to learn."

Polly Arango

New Mexico Parents Reaching Out

Governor's Task Force on Children, Youth, and Families

New Mexico Children's Continuum

Ms. Arango introduced her audience to New Mexico from the viewpoint of New Mexico's parents of children with special health care needs who have been working to improve the State's medical and educational systems. While New Mexico is a State of great physical beauty and diversity, it also faces many challenges:

- ★ One of seven New Mexico children lives in poverty.
- ★ New Mexico ranks 51st in the Nation in the percentage of women receiving prenatal care.
- ★ The State's teen suicide rate is dismal.

Therefore, New Mexico's families have arranged to make the lives of their children better, one family and one issue at a time.

Ms. Arango became involved as an advocate when she and her family learned that their youngest son, Nick, has cerebral palsy and developmental delays. As with many middle-class families, the Arangos discovered that few avenues existed to assist them as they struggled to pay Nick's medical and preschool bills. For example, although Nick was adopted, his adoption occurred before the emergence of adoption subsidies. Nick is an American Indian, but his birth parents chose not to enroll him in the tribe, a decision honored by Nick's adoptive family. As a result, Nick is not eligible for services through Indian Health Service or the Bureau of Indian Affairs. Because they were decidedly

middle class, the Arangos could not meet income guidelines for the State's crippled children program.

To deal with her frustration, Ms. Arango joined with other parents to found a statewide organization called Parents Reaching Out (PRO) for any and all families with children who have chronic conditions, disabilities, or illnesses of any kind. Twelve years later, PRO has 500 members who are from every part of the State and every ethnic background and who have children with many challenges. Many of PRO's members are the professionals, friends, and relations of families who have children with special health needs.

PRO began as an organization to provide peer support and information to families, and this function continues to be the heart and soul of its efforts today. However, PRO's parents soon tackled bigger issues such as writing the legislation that created a Comprehensive High Risk Insurance Pool for New Mexico. The list of issues they have addressed goes on and on. The following elements have contributed to their success in changing the system:

- ★ Ordinary parents have united to form a common bond.
- ★ They have forged strong partnerships with health, education, and other professionals.
- ★ One parent usually has risen to the forefront as a symbol of the movement.
- ★ Public and private agencies have supported the campaigns with technical assistance and in-kind contributions as a way of enlightening and educating the public.
- ★ At least one policymaker who is willing to "bleed and die" for the issue has become involved.
- ★ The highly visible work and people are supported by a broad-based grass-roots community of families and professionals who volunteer at home.
- ★ Everyone remembers the bottom line: improving the health of children and ensuring that their families can raise them with dignity, respect, and love.

Beverly McConnell

*Director, Parent Participation Program
Children's Special Health Care Services
Michigan Department of Public Health*

When Ms. McConnell's child required an oxygen tank, she had to learn about health care systems and how to make them work. Because of her experience, McConnell was hired by the Michigan Department of Public Health to work on a peer level with "weighty" issues for a newly created parent participation program. The program, born out of decentralization at the State level, needed more parent involvement at the local level. Ms. McConnell described the initial ambivalence of one supervisor who did not understand the need for parent involvement at the State level. However, as the program gained wide acceptance, she gained this person's full support.

Ms. McConnell's job was to build relationships; create task forces; make approvals; and set policies for hospitals, physicians, and home health services. She is proud of the fact that all hospitals in her State now need parent advisory committees and parent staff. She stressed the benefits gained from building relationships among parents, community, and government: the establishment of enormous power bases that took action when funding cuts were threatened. They influenced senators so that

"Families have both an immediate vested interest to get things changed and the freedom to act. ..."

parents received needed appropriations. They helped establish boilerplate in laws that required that families and consequences to them be considered before programs are changed or funds are withdrawn. In effect, the legislation mandated State government to work with families.

Ms. McConnell noted that parents are willing to take risks to support the continuance of needed services. "Even if they are not sure the steps are right," she said, "[parents] are willing to follow their instincts." Ms. McConnell introduced four strategies to help families meet children's special health care needs. (1) Support. State agencies should nurture and facilitate the development of statewide coalitions of and support groups for persons with disabled children. State agencies should encourage referrals to these groups. Financial support is also very important. Parent consultants must get reimbursed for their time and expenses. Another type of support involves helping parents acquire a wealth of knowledge. They need information, for example, about who in the community has had a bad experience with clinics, etc. (2) Dissemination of Information. State agencies must establish effective, routine mechanisms for receiving information from parents and parent support groups and for disseminating information to them (family support networks). Agencies must provide families with clear written information describing programs, services, and mechanisms for accessing those services. Agencies must provide ready access for parents to unbiased and complete information from their child's records. (3) Collaboration. Families that participate across the State must represent the cultural and economic diversity of the State. They must participate fully with professionals in policy development, program implementation, coordination of services, and evaluation of programs. State agencies must financially support parents involved in these activities. (4) Integration (the ultimate goal of services). State agencies must have a written policy that reflects the pivotal role of families. Integration recognizes the concept of family-centered services. However, parent input is needed to ensure that services are family centered. Therefore, mechanisms for parent and professional collaboration should be used routinely at all levels and in all program areas.

In closing, Ms. McConnell shared the following "lessons learned" from her experience: (1) Families have both an immediate vested interest to get things changed and the freedom to act (they have no boss in this endeavor, nothing to lose, and everything to gain). (2) Concepts trickle down to benefit health care for children in general, not just for those with special needs. (3) Financial support and encouragement are vital. (4) Advocacy can result from one-on-one relationships, either parent to parent or parent to professional. (5) None of the panelists are specialists in special health needs. In other words, parents should be recruited on the basis of their commitment, not educational degrees. (6) Gaining new territory is worth the risk.

Panel 4B

PARENTING: THE CRITICAL ROLE

As she introduced the speakers on this panel, Moderator Barbara Heiser of the La Leche League stressed the importance of parent involvement in children's lives both at home and at school. As children's main support system, first teachers, and caretakers, parents exert a lifelong influence on their children's development.

Ann G. Cagigas, R.N., I.B.C.L.C.

Lactation Consultant

For this panel's opening presentation, Mrs. Cagigas shared some of her experiences as the mother of three children, two of whom had severe sleep apnea as children. As infants, all of her children had to be constantly monitored lest they suddenly stop breathing. Mrs. Cagigas, a former emergency room/trauma nurse, found herself wholly devoted to a new, 24-hour, acute care detail at home. Her eldest daughter, who is now 13 years old, has fought several medical problems, including thyroid failure and Tourette's Syndrome. Mrs. Cagigas said she believes that the commitment she and her husband made to their children and their determination

to stay active in their roles as parents carried them through some difficult times. She also stated that breastfeeding her children as infants helped her to feel connected to them later in life and kept the maternal bond strong even during very stressful periods.

Mildred M. Winter, M.Ed.

Executive Director

Parents as Teachers National Center

University of Missouri - St. Louis

Ms. Winters presented the methodology and history of Missouri's Parents as Teachers program. Children are born learning, she said, "but they don't come with instructions." As children's first and most influential teachers, parents should help their children learn all they can. The Parents as Teachers program helps parents give children "good beginnings."

The key, according to Ms. Winter, is to reach children as early as possible. We learn more as children than we do during any comparable period of our lives. To make the most of this fertile learning period, the Parents as Teachers program promotes the development of a parent-school partnership. A home visitor program brings trained parent educators into the children's homes to talk with parents about opportunities for the child to learn, things the parents can do to stimulate the child's imagination, and what skills the

child should be developing. Home visitors also act as listeners and offer the parents support and a sympathetic ear. The Parents as Teachers program involves as **many** family **members** as possible, including fathers and grandparents. Any family is eligible to enroll in the program, and special efforts are made to attract low-income families and teenage mothers.

To date, four independent evaluations of the program have been conducted; all have shown that children whose families participated in the Parents as Teachers program to score higher in language development, intellectual development, and social development than children who were not involved in the program.

Thirteen states, including Missouri, have Parents as Teachers programs in place. Many use funds from Even Start, Chapter I, Chapter II, children's trust funds, private corporations and foundations, and public service groups such as the Kiwanis Club. In closing, Ms. Winters said that while the Parents as Teachers program does not solve all of the problems that face children and their families today, she and her organization are proud to be part of the solution.

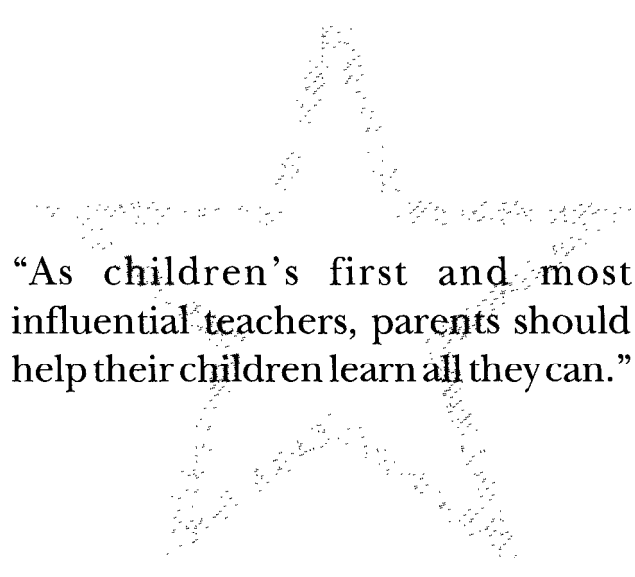
Following Ms. Winter's presentation, a member of the audience [Sandra McElhany of the National Mental Health Association] urged attendees to write their representatives in Congress to ask them to support an amendment to the Bill for Educational Research and Education that will be proposed by Senator Kitt Bond of Missouri. The amendment, which has the support of Senators Kennedy (Massachusetts), Dodd (Connecticut), and Pell (Rhode Island), would grant States funding \$20 million per year for 5 years—to start or expand Parents as Teacher programs.

Mary Louise Alving, M.Ed.

Project Director, Parent Leadership Training

Citizens Education Center

Ms. Alving presented a set of proven guidelines for setting up parent involvement programs. Although it is widely known that parent involvement improves children's self-esteem and school performance, 75 percent of parents still do not get involved. Ms. Alving offered ways to increase parent involvement in school programs. The Parent Leadership Training Project at the Citizens Education Center began in Seattle in 1986



"As children's first and most influential teachers, parents should help their children learn all they can."

“...parent involvement improves children's' self-esteem and school performance. ...”

to address the needs of Migrant families. Since then, it has expanded to include families and schools of all backgrounds.

Ms. Alving first talked about the four myths that people use to say that parent involvement is not practical. The first was that “parent involvement” means volunteering for school activities. Ms. Alving disagreed, saying that a parent who helps his child with her homework, or who takes an active role at school board meetings, is at least as involved as the volunteer. The second myth is that **parents** don't have time to participate in school activities. She pointed out that parents do come to school when they have what they think is a good reason (for example, debates about condom distribution in high schools). “Parents are hard to reach” was the third myth. Ms. Alving asserted that it is the schools, not the parents, who are unwelcoming. The fourth myth she confronted was the “at risk” classification of families from certain ethnic groups or economic levels. She said that all families are at risk at some time, and that these kinds of classifications promote division within the community.

Ms. Alving presented eight “do's” for successful **parent involvement programs**. These were repeated in the video that was shown at the end of the session.

- ★ All activities and programs should be based on the idea that all families have something to share.

- ★ Parent involvement programs should include members of other programs—such as Chapter I and Head Start—and should collaborate with other programs.
- ★ Most successful programs focus on the child's teacher. Parents want to meet and get to know their children's teachers. Teachers are often the best way to reach parents.
- ★ The program should be coordinated by a team; a good program will rapidly expand to a size where it simply cannot be administered by only one person. Teams should consist of the school principal, two parents, two teachers, a school district representative, a business/community representative, a social services professional, and a culture/language specialist (as required). Before the team begins planning, they should attend a 5-day training session.
- ★ Successful programs always allow room for adjustment. Every school is different, and programs must be adapted to fit their audiences.
- ★ Teacher training is an important part of parent involvement programs. Teachers often have no training on how to work with parents.
- ★ Ongoing funding for parent involvement programs should be obtained. Too often, when funding runs out, the parent involvement program goes with it. Begin to work for permanent funding early.
- ★ Building a developmental evaluation process into the program means that staff can evaluate their progress at any point and can make any necessary adjustments.

Letitia Rennings, M.S.

*Even Start Coordinator
U.S. Department of Education*

Last to speak in this session was Ms. Rennings, who discussed the Even Start program. This family literacy program has increased in Federal funding from

\$14,820,000 in 1989 to \$70 million in 1992. President Bush is recommending that funding for the 1993 fiscal year be \$90 million. There are currently 240 funded programs, including 9 Migrant programs. Even Start is open to children from birth through age seven living in a Chapter I elementary attendance area and a parent who is eligible for adult basic education.

Even Start is composed of three core components—parenting education, early childhood education, and adult education. The projects build on existing programs in the community, such as Head Start, Chapter I, Chapter II, adult education, programs for children with disabilities, JTPA, and JOBS. The program's goal is to break the cycle of illiteracy that plagues so many American families.

The benefits of Even Start's focus on literacy are many. Parents who learn to read develop an interest in school, and some of them choose to go back to school

as a result of their involvement. In addition, children feel proud of their parents and work to emulate their parents' academic success. In some projects, parents have formed their own support networks and have learned the importance of proper health care and nutrition, talking and reading to their children, and serving as good role models. The self-esteem and confidence of participants—adults and children alike—is greatly increased.

The results of first year (1989) program evaluations show that 70 percent of families served have annual incomes of less than \$10,000. Even Start has reached 45,000 adults and 48,000 children across the country. The majority of adult participants are between the ages of 21 and 29.

To close her presentation, Ms. Rennings offered the audience some specific illustrations of the good Even Start can do for families and for whole communities. She



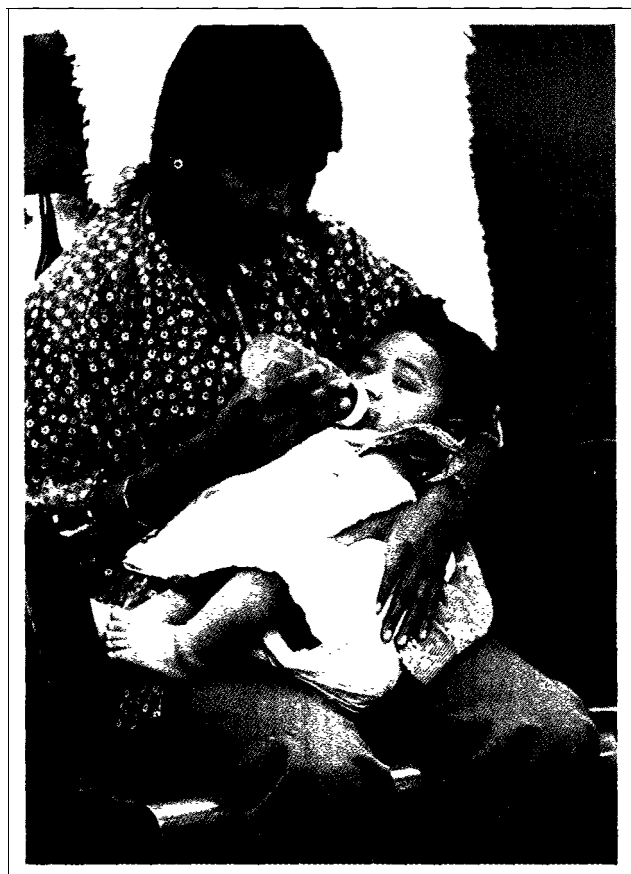
briefly described three successful programs—one in a trailer park in Fort Collins, Colorado, one in a very poor community in Sneadville, Tennessee, and one in the town of Hidalgo, Texas, on the Mexican border. Each of these programs has tailored its services to fit the specific needs of the community and families it serves. Recognizing that families' basic needs must be met before they can begin to apply themselves to studying, the Colorado program offers not only General Equivalency Diploma (GED) training for parents, but also teaches parenting skills, basic nutrition, and hygiene, and coordinates a food donation program. In Sneadville, where many people have never been inside a school building, 150 families—almost everyone in the county—is involved in Even Start. More than 500 people attended the program's spring picnic, with everyone in the community participating. The town sheriff cooked, and the staff of the barbershop gave free haircuts—some to women who had never had their hair cut by someone outside their immediate family. At the end of the year, 48 women enrolled in Even Start had passed the GED and 10 of them received drivers' licenses.

In Hidalgo, Texas, the Even Start program serves a community that is mostly Hispanic and poor; the families participating in Even Start had no plumbing or sewer systems. Their homes resembled small toolsheds. Nearly 120 parents and 130 children are enrolled in the program. Before Even Start came to Hidalgo, many women, who had had even less education than their husbands, were completely illiterate. Many families were entitled to food assistance, but could not negotiate the system because they could not read. The Hidalgo Even Start home visit has proved the most effective means of improving families' literacy skills in a culturally sensitive manner and of assisting families in dealing with social service agencies.

Panel 5A

CHILDCARE: TWO PERSPECTIVES

Childcare can be viewed from two perspectives: that of the parents and that of childcare providers. This panel, moderated by Barbara A. Willer, Ph.D., Public Affairs Director for the National Association for the Education of Young Children (NAEYC), presented the results of two national childcare surveys, one from each perspective. Dr. Willer noted that these projects, which were separately funded and designed, are unique because they highlight partnerships (collaborations). The first study was the National Childcare survey sponsored by NAEYC and the Administration on Children, Youth, and Families, U.S. Department of Health and Human Services. The study used a telephone survey of parents designed and analyzed by the Urban Institute. It explored general questions about childcare arrangements



and included substudies of low-income families and military families. The second study, the Profile of Childcare Settings, was sponsored by the Department of Education. The study dealt with the supply of childcare services, use by low-income families, range of services, and quality.

Patricia Divine-Hawkins

Public Affairs Co-Director

National Association for the Education of Young Children

Ms. Divine-Hawkins reported immense change with respect to childcare in this country in this generation. In the 1990s, many mothers are working, resulting in a large proportion of children in preschool and a large number of children caring for themselves. She also reported a shift from informal toward formal childcare centers and homes. Census studies of parents and national studies by the Administration on Children, Youth, and Families point toward these conclusions. She noted that the consumer studies of 1974 through 1976 were prototypes of our understanding of childcare, but they did not include family daycare providers.

According to Ms. Divine-Hawkins, social policies of the 1990s are oriented more toward children and the family. Childcare is a central component of employee benefits in many companies. Head Start created new partnerships between Federal, State, and local governments. The continuity between early childhood education programs and elementary school has enhanced and eased the transition between early childhood and kindergarten. However, these social factors create a complex situation and thus a need to look at childcare issues more holistically.

Ms. Hawkins-Divine related that NAEYC's research examines how the supply of and demand for childcare work together. It is the first research that (1) studies the range of options for different families in different types of situations, (2) explores characteristics of individual families, (3) develops a comprehensive database with individual data tailored to individual circumstances, and (4) examines socioeconomic factors. NAEYC also emphasizes the importance of partnerships in addressing childcare issues.

Sandra L. Hofferth, Ph.D.

Senior Research Associate

Human Resource Policy Center

The Urban Institute

Dr. Hofferth was the principal investigator of the National Childcare Survey, which explored supplemental care for children (center care, family daycare, in-home care, care by a relative, or no supplemental care). The components of the survey included the number of households with children under certain ages, number of children enrolled in daycare, a parent survey, and a provider survey. The survey revealed a high percentage of supplemental care and a major shift in the providers of supplemental care: more and more children who receive care out of the home are enrolled at centers as opposed to receiving care at homes of relatives. The survey examined primary care for the youngest preschool child by income, for employed mothers. Enrollment in center-based programs has increased particularly among lowest income families whose children are placed in subsidized programs and who receive direct financial assistance, etc. The working poor and low- to middle-income families, by contrast, are participating at a lower rate in center-based programs. Dr. Hofferth said it is noteworthy that the cost of care has not increased significantly relative to the cost of living. But, she affirmed, as the high-income families get tax credits and low-income families get assistance, the middle class gets squeezed out.

Dr. Hofferth's research shows that parents learn about childcare arrangements for the youngest child through relatives, friends, and neighbors (informal networks) and from referrals. The most important factors for measuring daycare are quality (above all else), reliability, teacher training, and student-to-teacher ratios. The survey found that parents were generally satisfied with daycare arrangements. One-fourth of the parents surveyed wanted to change arrangements. Of those, one-half wanted to switch to childcare centers. Childcare centers are the preferred alternative. Interviews with surveyors showed that some centers were regulated, and others were not. Nonregulated centers outnumbered regulated centers. Nonregulated centers differed from regulated ones in

that they were smaller, had shorter operating hours, charged less, and were not run by professionals. The major findings were that, during the preschool years, more and more children are in childcare centers and some, especially the poor, may be suffering.

Elizabeth Farquhar, Ph.D.

Program Analyst

Department of Education

Dr. Farquhar talked briefly about the Department of Education's role in creating policies and studies concerning early childhood education, childcare, and family education. The Department of Education supports Chapter I creation of Even Start for adults in need of literacy skills. Preparing Young Children for Success is a Department of Education program that prepares children for schools. The Department also sponsors the Profile of Childcare Settings Study. The Department also collaborates efforts with the Department of the Health and Human Services. Since the 1980s, the Department has worked with the States, who became active in developing preschool programs. "Collaboration," Dr. Farquhar stated, "is very effective in these studies."

Ellen Eliason Kisker, Ph.D.

Senior Researcher

Mathematica Policy Research, Inc.

Dr. Kisker, who directed the Profile of Childcare Settings Study, described her extensive research on the supply of childcare for preschool and school-age children and on childcare utilization by low-income mothers in terms of two aspects: availability and quality. Dr. Kisker discussed availability in terms of formal early education and care at centers and at regulated family daycare programs. She found that the number of programs has tripled and enrollments have quadrupled since the 1970s. She confirms that utilization rates are high and that most vacancies are concentrated in fewer than one-half of daycare facilities. However, more information is needed from parents to determine if shortages exist in specific areas for certain types of children. Dr. Kisker noted that not all programs provide all services. As a starting point, one can look at admissions policies and determine whether the

facility accepts infants, children who need full-time services, and handicapped and/or sick children.

In terms of quality, Dr. Kisker noted, daycare centers can take many forms. "A daycare center that is considered quality," said Dr. Kisker, "promotes child development. . . . You can't assess childhood development by individual child, but there are certain indicators of quality." These indicators include (1) average group size, by various ages (look at the various laws pertinent to the regulations); (2) average child-staff ratios, by various ages; (3) teacher qualifications, by type of degree; (4) teacher turnover (profit versus nonprofit), and (5) parental fees (not changed since 1970s if adjusted for inflation).

The Childcare Settings study led to new childcare policies. The 1990 baseline data were used to assess what has happened since the early education initiatives were developed, and programs have since been implemented. To illustrate Dr. Kisker's statement, Ms. Divine-Hawkins shared that 32 projects in 32 States have evaluated the transition of Head Start graduates over the next three grades, assessed their progress, and determined under what conditions they progress.

Panel 5B

HEALTHY START, HEAD START, EVEN START, AND WIC: INTEGRATING HEALTH, EDUCATION, AND SOCIAL SERVICE PROGRAMS

Wade Horn, Commissioner of the Administration for Children, Youth and Families, served as moderator for this session on collaboration among various health and social service agencies.

A. Kenton Williams, Ed.D.

Associate Commissioner

Head Start Bureau

"Head Start is alive and kicking because it works." So Dr. Williams, the newly appointed Associate Commissioner for the Head Start Bureau, opened his discussion of the

Head Start program. Head Start is a comprehensive child development program that works with the whole child to promote self-esteem, education and literacy, and health through four channels: education, health services (including medical, dental, psychological, and nutrition), social services, and parent involvement. President Bush has recommended that Head Start be allocated \$600 million for the coming fiscal year. Head Start is proud of its cooperative relationships with other programs and agencies, including the Health Care Financing Administration, the Public Health Service, and the Department of Education.

Dr. Williams said that he is happy to be working with such a successful program and named the following priorities for Head Start in the coming year

- ★ To better serve pregnant women and to provide optimal prenatal care to keep mothers healthy and to help them bear healthy children.
- ★ To maintain continuing relationships with primary care physicians.
- ★ To improve clients' access to secondary care.
- ★ To provide referrals to appropriate psychological counseling, substance abuse treatment, etc.
- ★ To reduce the number of low-birthweight babies and to reduce the infant mortality rate.
- ★ To improve clients' understanding of wellness and increase personal responsibility for health, including cessation of cigarette smoking, alcohol or substance abuse, etc.

Donna F. LaVallee, M.S.

Nutrition Coordinator

New Visions for Newport County

Dividing her work week between WIC and Head Start in her job as nutrition coordinator **for this program** in Newport County, Rhode Island, Ms. LaVallee had many insights about how to integrate efforts between these programs.

Because WIC and Head Start serve the same population, both programs and their clients benefit when they work together. Ms. LaVallee offered many simple sugges-

tions to help foster collaboration between local WIC and Head Start offices, such as open houses, cross-referrals, membership on each other's policy committees, guest speaker exchanges, and assistance in program evaluation. Because WIC and Head Start have so much in common, they can share many things, including resources, cosponsored clinics and health fairs, joint newsletters, all-in-one application forms, community needs assessment data, and more. Ms. LaVallee urged program staff to "communicate, cooperate, and coordinate."

Thurma McCann, M.D., M.P.H.

Acting Director, Office of Healthy Start

Health Resources and Services Administration

Dr. McCann described the Healthy Start program, which is based on recommendations from the President's Commission on Infant Mortality. Now in its early stages, Healthy Start is being implemented in 15 communities with the aim of reducing infant mortality in those communities by 50 percent.

Program applicants were required to meet five basic criteria to have their proposals considered: (1) innovation in delivery systems (e.g., user friendliness, etc.), (2) community commitment to Healthy Start's goals, (3) the ability to offer increased access to health care to reduce low birth weight and other causes of infant mortality, (4) integration of medical and social services, and (5) multiagency participation. As a whole, the Healthy Start program is unique in that it allocates unprecedented resources to prenatal and perinatal care, mandates community choice and flexibility, and empowers communities to build the kinds of programs that will work best for them.

Although Healthy Start funding lasts for only 5 years, Dr. McCann stressed that a community that has "bought into" the program can find a way to keep it in place even after Federal funding is withdrawn. Healthy Start encourages community involvement and has won support from various churches, civic groups, tribal councils, schools, and business organizations. Such agencies as the Public Health Service, the Health Care Financing Administration, the Department of Education, and the Department of Health and Human Services are also active partners in the national program.

Patricia A. McKee

*Chief, Grants Administration Branch
Office of Elementary and Secondary Education
U.S. Department of Education*

Now in its third year, the Even Start program is proud of its cooperative relationships with other agencies and within the communities it serves. Ms. McKee presented a brief overview of what Even Start is doing in this area.

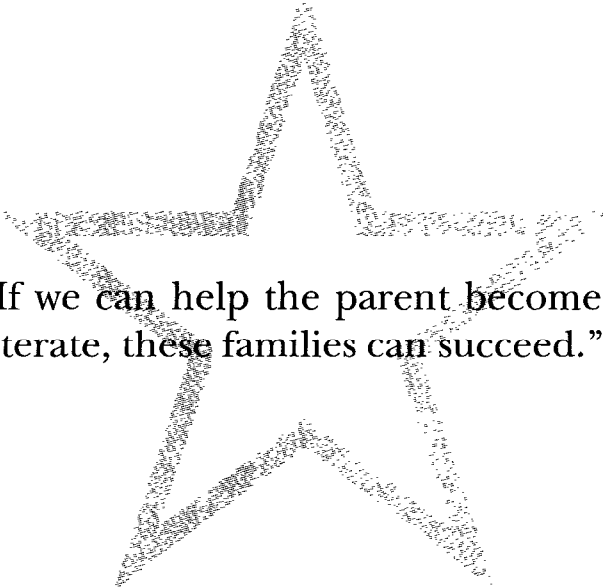
When Even Start was mandated by Congress 3 years ago, part of that mandate required that Even Start work with other agencies to achieve their common goals. The 76 programs established to date contain a total of 869 collaborative arrangements for primary (or “core”) services and 1,600 collaborative arrangements for support services. More than 67 percent of all Even Start programs work with their local Head Start programs.

Howard T. Miller

*Coordinator
Even Start Family Literacy Program
Prince George’s County Public Schools*

Mr. Miller opened his presentation with a brief overview of the statistics on illiteracy in America and what it costs. More than 40 percent of all military service enlistees are functionally illiterate. More than two-thirds of all U.S. colleges must offer remedial English classes. More than one-half of all prison inmates are functionally illiterate. He stated that these and other data show that the deleterious effects of illiteracy lead to financial losses, crime, violence, poverty, and depression. Even Start’s approach in Prince George’s County is based on two important assumptions: (1) parents’ level of educational achievement affects their children’s success in school and (2) a child raised in a literate home will naturally learn to read, just as he will learn to talk and to feed himself, through learning “reading behaviors.” The second assumption is called “emergent literacy.”

Mr. Miller stressed the importance of educators’ getting to know the families of the children they teach, to form a cooperative partnership between the school and the parent. Parents who are enrolled in the Even Start program along with their children are able to go to class when it is convenient for them, and transportation is provided. Parents learn new skills in preparing for the

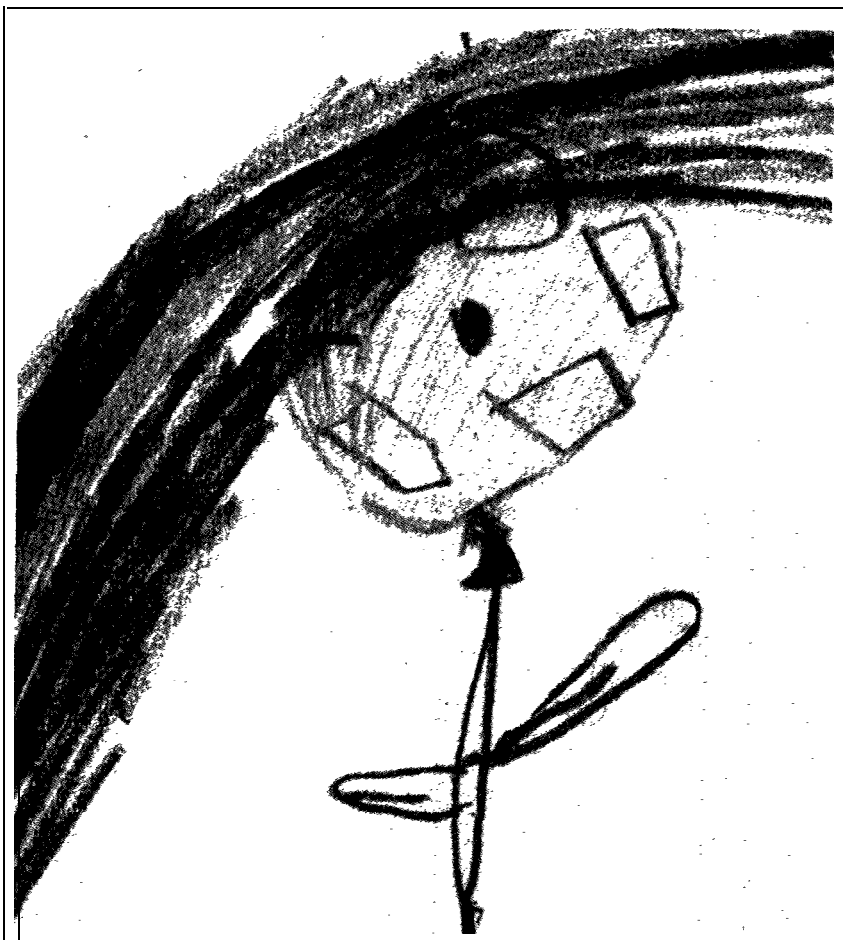


“If we can help the parent become literate, these families can succeed.”

GED, and they also learn parenting skills that help them teach their children. General health and nutrition services also play an important part in helping families to learn and grow together; recognizing this importance, Even Start coordinates closely with Head Start, WIC, the Cooperative Extension, and schools. “If we can help the parent become literate,” Mr. Miller said, “these families can succeed.”

Chapter 7

Closing Remarks



Chapter 7

Closing Remarks

Antonia C. Novello, M.D., M.P.H. *Surgeon General*

I have only a few comments. I think that today you have seen that when people get together, things work. But I can also tell you I am proud of your three capable representatives who communicated your wisdom about what this country needs and what this administration can do to solve our problems. This was unrehearsed; it was collectively put together; and I think it probably represents us better than anyone talking from their own pain. This is what makes this Conference unique. Moreover, it's even more difficult for me to speak after having heard people like this. I also can tell you that, when this Conference is done and when we all go our separate ways back to the States and communities, my impression will be that we have come together for only one purpose, and that's the purpose of taking care of children and families.

The President said his vision is that, in the year 2000, this country and these children are going to move forward. The children of today will be the explorers, writers, teachers, doctors, and inventors of tomorrow. President Bush said that, in America, families come first, and that's what makes this conference unique.

You are here from 50 States and from Territories as far away as Guam. You are here from Puerto Rico, and you are here from everywhere. Contrary to what the only reporter that has come aboard asked yesterday, you are not all Republicans. In this Conference, I have taken great pain to make sure that we are not labeled by ethnicity, language, or gender. We are here with only one mission, no matter where we come from and who we are. That mission is to care for the children and families of this country.

You have articulated what you need, and I have never heard it so well expressed. This Conference is focused on our children, and we're working toward the benefits of every child. I have been much more impressed than ever by people who perhaps never knew

they could speak for others and be taken seriously. We said this is about respect, respect across the board. I think in these 3 days, we have shared the commonality that, even if you don't speak the same language, it doesn't mean that you are not intelligent. Most importantly, we recognize that "poor" is a transient state of mind: today, it is you; tomorrow, it can be me. So let's not only be culturally sensitive, let's also be culturally responsive. I think this Conference has concentrated on that.

Whatever personal circumstances we brought here-and I can assure you that some of your faces said, "Show me," and some of your faces said, "One more conference; don't bother me with trivia"-I can assure you that by having come here for whatever was the message you thought you wanted to bring, you have advanced the field of every child, and you will perhaps be as responsible for having made one more child part of these United States by just having been here. For that you should be complimented.

We came here to deal with awareness, transition, and participation. After having listened to the parents, you realize that parents do all three at once, and sometimes one parent does it all. I hope now that you realize parents are crucial for whatever we're going to do in this country for the families. If you don't believe me, then I want to know where you've been for the last 3 days.

When I charged you on Monday, I told you I was going to ask the best of you. But I warn you, I'm going to ask even more of you, even when you think you're going to go home and forget about this Conference. I can tell you that we've heard the parents and the groups. I've felt the pain, and I've talked to you. I've talked to every one of you individually or collectively. When we leave this place, we will have everything that's been said included in a proceedings compendium. We will complete the document as quickly as possible, but remember we must go through the General Services Administration and General Accounting Office to have it printed. We're going to make sure that this goes to every Governor, every one of you, and every legislator who asks for it; right now the Hill is also clamoring for it. So this is going to be a public document for all of those who need it.



But the document will be just a document if you do not work with us to make it a reality. You were able to see that our officials are committed, but don't ever put the rights and the benefits of your family only on some other people's shoulders. You have to share the responsibility; otherwise, it will not become a reality. The reforms of this country will come forward through the families; the parents spoke today, and they no longer want to be silent partners. They want to be activists and advocates, and to do that you also have to speak for yourself. Otherwise, we're not going to get anywhere. I also heard that parents, especially fathers, have to be part of everything that we do. I think, as I've said before, we have to find ways by which we bring fathers into the family, not ways by which we keep them away. I know that parents have to be respected as experts, and it is imperative that we do that.

Another big area is the need for flexible hours, and in immunization, we have discovered that repeatedly. Hours from 8:30 [a.m.] to 5:00 [p.m.] is a beautiful protocol, but 67 percent of the parents work in a job

they cannot afford to leave for 1 hour and vaccinate a kid, and 2 1 percent of this country's families are headed by a single parent. Open the clinic when the parents can come, if you really are serious about immunizing. For once, "Put your money where your mouth is."

We must make sure that we write in the language that people understand. Yesterday, I was in a transplantation meeting, and they told me I need bilingual permits to donate my organs. And they say minorities do not donate. Would you donate your organs by signing a document given to you by a person who is not culturally sensitive, in a language that you do not understand? If you sign, I have a bridge I want to talk to you about. This Department is making sure that everything is put in the language that people will understand. Most importantly, some of our groups have no more than an 8th grade education. So again you said it, "Put it in words that people understand." In medicine, we're always talking about EKG [electrocardiogram] and EEG [electroencephalogram], and I asked a doctor, "What is an EGG?" He didn't know, so I told him, "an egg."

It's also important to remember that the country is full of children having children. We have to worry about them, too. They do not love their children less because they are children themselves. They are going to need understanding, and they are going to need us to help them, too.

Self-esteem was another issue raised here. Self-esteem is no longer just for the child. It also has to come from the parents, and that is something that we cannot buy. Medicare, Medicaid, nor Social Security can buy it. That has to come from within. But we cannot only think of self-esteem for the children. We have to give it for the parents. Occasionally, take your time to tell us when we do good, and, occasionally, just forget that we did bad. I think positive is part of where we have to go.

One woman said we have to help people to help themselves, rather than offer programs that foster dependency. I agree. I have the feeling that that should be a way we should move toward our goal. We might use different words. We might say "advocacy" or "empowerment." Either way, we need a little more positivism in getting together.

“... this Conference has done one thing beautifully: It has vindicated the parents. It has helped people realize that they can no longer be silent.

The title of the Conference has been “Healthy Children Ready to Learn: The Critical Role of Parents.” I do believe-and I hope you do, too-that this Conference has done one thing beautifully: It has vindicated the parents. It has helped people realize that they can no longer be silent. No single program in this country should be done in the absence of the parents’ participation; otherwise, it will be one more useless piece of paper.

I said in my opening remarks that this Conference was the result of 18 months of planning. I believe that is totally obsolete at the end of these 3 days. This is just the beginning, not the end of 18 months. I have seen all my Assistant Secretaries involved in this with me, and we’re going to make sure that whatever we plan will be with families, parents, and children in mind. For that reason, this is a success story.

I know I told you not to ever get discouraged with the Federal Government. It’s a powerful one, and you have to learn how to use it as a tool. Today you had everyone at the top discussing how they see it. As I told you, perception versus reality is the problem here. You might perceive one thing, and the reality might not be so bad, but I think it worked on both sides of the table. You have heard from all of us-from the Secretary of Health and Human Services, the Secretary of

Agriculture, the Secretary of Education, six Assistant Secretaries, and the President of the United States. But most importantly, we heard from you. That’s what makes this Conference unique. I think we should never underestimate the power of a coalition. Alone, we are not going to do anything, including the President himself. We all have to be able to tell the Government we’re here. We’re part of the solution. Please, let’s not be part of the problem. I want all of us to get together, regardless of what we felt when we came here, because united we can do a lot of work. I know that you probably have thought, “She’s going to repeat herself again.” No one alone can work. We have to unite.

But I also told you to use anger if necessary. I can tell you that I feel good that you did, because when you used anger, you were collectively expressing something that I hope the Conference has alleviated. Perhaps now you at least know a place where you can find a solution for your problem. I know that I have told you that we have to be creative. Part of this world is discouragement, but I’m not going to let anyone use it to take care of you or me. Discouragement is a state of mind.

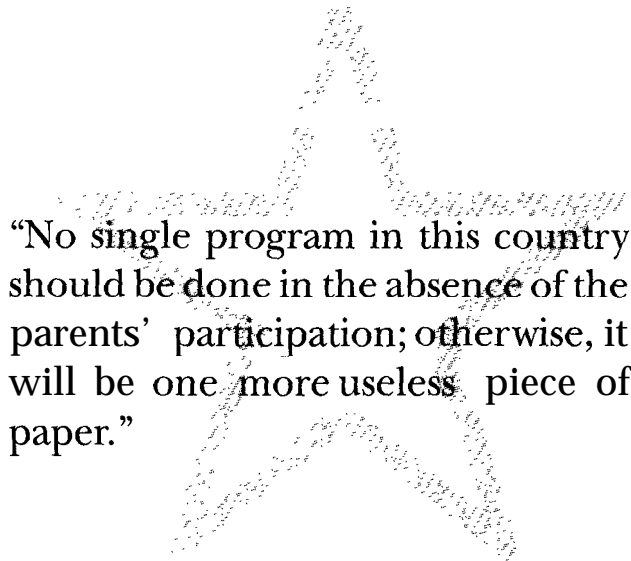
I ask you to join me to share the responsibility for making your family and your children well. Share with us at the local and at the State and at the National levels and in the public and the private sectors. It’s no longer one person’s responsibility. There is too much at stake!

So look at everything that works, and look at everything you think needs to be replaced. Then call and cajole and make sure that you get involved. I know that we are “conferenced out,” but I know also that we are accelerated to the “max.” You have to use that momentum when you get back to work and to your communities and say, ‘You know when the Surgeon General, the Secretaries, and the President speak, they are committed to make the family top priority.’ Let’s get real. Let’s get real! I can tell you that when the experts go home, they are not going to be devoid of work because I am not going to be devoid of work. I have your telephone numbers, your fax numbers, and even your grandfather’s numbers. So, rest assured that this is not just the ending of 3 days, but it’s the beginning of a coalition of parents taken seriously, trying to

determine, through their collective actions, what this government can do for you. I'm with you. Are you with me?

I want to bring six people to the podium because without them I don't think we could have done this. They are the three parents' representatives and the three parents' alternates. I think we should give an applause to our panel. We had six parents, three to come forward and three to be available in case they fainted. Obviously, we didn't need the other three, but they were there and ready to go. So, I would like to do something. There's not much I can do for you all, but I can certainly give what I call the Surgeon General's Certificate of Appreciation, and believe me, I do not give that too freely. But, when people give of themselves, as they did to represent you, I think a Certificate of Appreciation from me is just the first step. I think that you should be able to thank these six people who represented you so well. Because without them, and you, this Conference would have never happened. So how about if we applaud for all of us. Ellie Valdez-Honeyman, Larry Bell-I am eating squash all my life—Sandy Slavet, Rosa Palacios, and Jesus Sada. Sherlita [Reeves] had to go and pick up her little child, so we'll keep Sherlita's and mail it to her.

We might be "conferenced out," but I think we are motivated to go out there and do a lot for what we have tried to accomplish. Most important, is that, collectively, we will be able to do it. This document will not stay on anybody's shelves; I guarantee you that. So today's the beginning, but I need you. Remember, united we will succeed. Separated, we will not get anywhere. Today's the first day. Thank you for coming, and God bless you.



"No single program in this country should be done in the absence of the parents' participation; otherwise, it will be one more useless piece of paper."

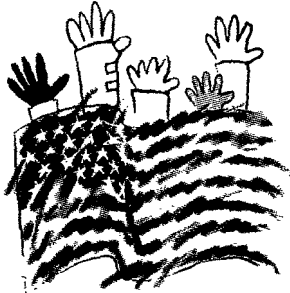
Conference Participants

Appendix A

State Parent Delegates¹

The Surgeon General's Conference

HEALTHY CHILDREN



---Ready to Learn---

The Critical Role of Parents

Washington, DC

February 9-12, 1992

Alabama

Susan Colburn
Montgomery

Letitia Hendricks
Montgomery

Susan Watt
Childersburg

Alaska

Esther Johnson²
Augustine

Danielle Madigan
Elmendorf

Sue Wilken
Fairbanks

American Samoa

Karen Ho Ching
Pago Pago

Iutita Savali
Pago Pago

Faafetai Seumany
Pago Pago

Lui Tuitele
Pago Pago

Arizona

Pamela Jones
Phoenix

Ernesto Meza
Phoenix

Pamela Morrison
Phoenix

Jerry Pearson
Phoenix

Arkansas

Pamela Ashcraft
Little Rock

Mary Blanchard
Blytheville

Deborah Frazier
Little Rock

Barbara Gilkey
Little Rock

Angela Lee
Little Rock

Nancy Lovette
Blevins

Hazel Murray
Pocahontas

Mary Ann Pickard
Searcy

Sherlita Reeves
Paragould

Linda Spence
Blytheville

Dinah Wells
Manila

California

Anna Cortez
Norwalk

Ann Kinkor
Rancho Palos Verdes

Colorado

Diane Reeves
Denver

Ellie Valdez-Honeyman
Arvado

Connecticut

Judy O'Leary
Trumbull

¹To protect their privacy, addresses of the State Parent Delegates have been omitted. However, the parents had the opportunity to exchange addresses and phone numbers at the Conference.

²Attended the Native American Parent Work Group.

³Attended the Migrant Parent Work Group.

Delaware

Laurence Bell
Laurel

Laura Ivansons
Newark

District of Columbia

Goldie Anthony-Henry
Washington

Dona Brawner
Washington

Brenda Calloway
Washington

Joan Christopher
Washington

Rosalind Coleman
Washington

Connie Dudley
Washington

Cristina Espinel
Washington

Lisa Holland
Washington

Susie King
Washington

Tawana Kinney
Washington

Maria Meehan
Washington

Kurt Stand
Washington

Lorraine Street
Washington

Florida

Kenneth Chambers
Tallahassee

Romero Cisneros³
Wauchula

Shirley Herbert Kendall
Lauderdale Lakes

Georgia Pappas
Jarpon Spring

Wendell Rollason³

Immokalee

Jesus Sada³
Ruskin

Lisa Spikes
Tallahassee

Annette Townsend
Tallahassee

Felix Valle³
Immokalee

Connie Wells³
Wauchula

Verdule Youyoute³
Zolfo Springs

Georgia

Anne Butts
Atlanta

Tina Doucett
Columbus

Louise Harris
Clarkesville

Porter Harris
Clarkesville

Gen Hunter
Atlanta

Glenda Welch
Gainesville

Sarita Welch
Clayton

Guam

Mae Ada
Agaña

Margaret Artero
Agaña

Hawaii

Susan Rocco
Aiea

Lanette Teixeira
Honolulu

Helen Usvale
Honolulu

Idaho

Marcia Hallett
Boise

Carolyn Kopke
Boise

Illinois

Marion Cooper
Chicago

Pat Doherty-Wildner
Chicago

Rosemarie Frey
Wheaton

Mitzi Montgomery
Sauk Village

Catherine Raack
Wheaton

Debra Zurkamer
Springfield

Indiana

Carol Burkes
Martinsville

Mary Snyder
Martinsville

Iowa

Gloria Klinefelter
Dubuque

Jean Linder
Johnston

State Parent Delegates

Kansas

Judy Moler
Topeka

Josie Torrez
Topeka

Kentucky

Rhonda Henning
Louisville

Gleason Wheatley
Frankfort

Louisiana

Joan Caloway
Shreveport

Tammy Rodgers
Baton Rouge

Leah Schwartzman
Baton Rouge

Charles Tyler
New Orleans

Maine

Annette Cohen-Hyman
Kennebunkport

Jenifer Van Deusen
Augusta

Mariana Islands

Victoria Mendiola
Tinian

Severina Ogo
Rotas

Rosa Palacios-Power
Saipan

Rita Sablan
Saipan

Catalino Sanchez
Saipan

Elizabeth Torres-Untalan
Saipan

Maryland

Kathy Cooper
Bel Air

Mona Freedman
Baltimore

Shawn Fritz
Frederick

Barbara Mallonee
Annapolis

Gordon Mallonee
Annapolis

Valarie Phillips
Baltimore

Massachusetts

Deirdre Ahneida
Amherst

Rosalie Edes
Concord

Sandy Slavet
Randolph

Michigan

Charlotte Boatmon
Quincy

Myra Charleston
Detroit

L. Bryn Fortune
Farmington Hills

Celia Garza
Detroit

Luz Teresa Hernandez
Detroit

Minnesota

David Becker
St. Paul

Roxanna Lee Foster
St. Paul

Mississippi

Patty Appleton
Jackson

Gwendolyn Fortson
Jackson

Robert Fortson
Jackson

Patricia Hych
Tupelo

Missouri

Alan Killingsworth
Springfield

Stephanie Mason
St. Louis

Deborah McDannold
Columbia

Carol Mertensmeyer
Columbia

Ellen Moses
Creve Coeur

Donna Snead
Kansas City

Montana

Lea Bear Cub
Brockton

Ellen Bourgeau
Missoula

Marilyn Femelius
Missoula

Julie Flynn²
Wolf Point

Doreen J. Fowler
Wolf Point

Karen Moses
Helena

Sue Phelan
Helena

Nebraska

Susan Christensen
Omaha

Cyndia Eckhardt
Lincoln

Nevada

Patti Miier
Reno

Robert Miier
Las Vegas

New Hampshire

Carol Barleon
Bow

Brenda Copp
Manchester

New Jersey

Joan Applebaum
West Trenton

James Brown
East Orange

Camelia Leach
Newark

Rhonda Nichols
Newark

Ciro Scalera
Newark

New Mexico

Kathryn Brown²
Taos Pueblo

Shirley Chaves
Española

Yvonne Gomez²
Taos Pueblo

Patricia Solomon-Thomas
Laguna

New York

Marvina Heywood
Utica

Bob Shannon
Buffalo

North Carolina

Gail Dunton
Arden

Gwendolyn Parker
Chinquapin

Meg Sawicki
Charlotte

North Dakota

Mary Ann Anderson
Bismarck

Nanci Cooley
Grand Forks

Ohio

Sandy Barber
Wauseon

Judy Minatodani
Solon

Peter Somani
Columbus

April Thorns
Reynoldsburg

Oklahoma

Pamela Hunt²
Skiatook

Marcia Lemons
Oklahoma City

Mary Littles
Midwest City

Linda Terrell
Oklahoma City

Susan Webb
Norman

James Wiion
Cushing

Oregon

Paula Bender-Baird
Enterprise

Jean Josephson
Portland

Katherine Weit
Portland

Pennsylvania

Kisha Henley-Davis
Harrisburg

Loaiza Manzo
Harrisburg

Frank Meredick
Plymouth

Ralph Warner
East Greenville

Mary Wood
Hadley

Puerto Rico

Sonia Benitez
Cataño

Maria Burgos
Canovanas

Abigail Muñoz Alverio
Caguas

Rafael Sanabria
Santurce

Ahna Socorro De Leon
Caguas

Rhode Island

Linda Dee Bryan
Providence

William Bryan
West Greenwich

Cindy Flores
Coventry

Patrice Richardson
Barrington

Janet Samos
Warwick

South Carolina

Betty Baker Davidson
Columbia

Debra Derr
Columbia

South Dakota

Julie Darger
Pierre

Glenda VanderPol
Academy

Tennessee

Michael Allen
Monterey

Sherry Allen
Monterey

Linda Lemons
Memphis

Phyllis Medlin
Cookville

Texas

Holly Craig
Grand Prairie

Darlene Dubicki
Austin

Norma Heredia
Arlington

Priscilla King
Georgetown

Leslie Lanham
Austin

Candy Sheehan
Coppell

Maria Vargas
El Paso

Utah

Brent Briggs
Sandy

Becky Hatfield
West Jordan

Vermont

Cathy Crow
South Burlington

Susan Rump
Thetford Center

Clark Sutton
Middlebury

Megan Sutton
Middlebury

Karen Witkin
Essex Junction

Virgin Islands

Mark Benoit
St. Croix

Verona Charlemagne
St. Thomas

Joyce Lebron
St. Thomas

Patricia Nobbie
St. Croix

Catherine Rogers
St. Croix

MaryAnn Weston-Livisay
St. Thomas

Virginia

Loretta Byrd
Richmond

Peggy Singleton
Oakton

Cherie Takemoto
Alexandria

Marilyn West
Richmond

Washington

Raúl Arambul³

Oralia Garza
Wapato

Kathy Johnson
Zillah

Felix Montes³
Sunnyside

West Virginia

Lorna Adkins
South Charleston

Bob Craig
Farmington

Kathy McCullough
Charleston

Barbara Merrill
Charleston

Jane Vance
South Charleston

Wisconsin

Ody Fiih
Hartland

Patty Peterson
Cashton

Patty Skenandore
De Pere

Wyoming

Desiree Lopez
Rawlins

Carole Palmer
Cheyenne

General Participants

Carolyn Abdullah
Center to Prevent Handgun
Violence
Washington, DC

Steve Abrams
U.S. Department of Agriculture
Food and Consumer Services
Washington, DC

Shellie Abramson
U.S. Public Health Service
Washington, DC

Irene Adderley
Washington, DC Public Schools
Washington, DC

Jeanette E. Akhter, M.D.
National Perinatal Association
Bowie, MD

Katrina Alaman-Murray
National Association of Social
Workers
Washington, DC

Lamar Alexander
Secretary of Education
Washington, DC

Robert E. Alexander
U.S. Department of Education
Office of Migrant Education
Washington, DC

Barbara Aliza
Association of Maternal and
Child Health Programs
Washington, DC

Dorothy J. Allbritten
National Association of
Children's Hospitals and
Related Institutions
Alexandria, VA

**Myron Allukian, Jr., D.D.S.,
M.P.H.**
Boston Department of Health
and Hospitals
Boston, MA

Mary Louise Alving, M.Ed.
Citizens Education Center
Seattle, WA

Rita L. Amadeo, M.D.
Easter Seals
Gwaynabo, PR

Maureen Ambrose
Pennsylvania Department of
Education
Harrisburg, PA

Robert W. Amler, M.D., M.S.
U.S. Public Health Service
Atlanta, GA

Kim J. Amos
National Center for Clinical
Infants Program
Arlington, VA

Polly Arango
Algodones Associates
Algodones, NM

Ann Armstrong-Dailey
Children's Hospice International
Alexandria, VA

Susan Austin
National Association of Federal
Education Program
Administrators
Philadelphia, PA

Corinne Axelrod
U.S. Public Health Service
Rockville, MD

Laura Diaz Baker
Puerto Rico Federal Affairs
Administration
Washington, DC

Wendy Baldwin, Ph.D.
National Institutes of Health
Bethesda, MD

Linda V. Barnett
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Rosemary Ramirez Barbour
U.S. Department of Education
Washington, DC

Sandy Bastone
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Pat Bayer
American School Food Service
Association
Alexandria, VA

Mae Beck
Black Coalition of Concerned
Citizens for Child Care
Dallas, TX

Juliane Becket
University of Iowa
Cedar Rapids, IA

Julie Beckett
Federation for Children with
Special Needs
Boston, MA

Arlene Bennett
National Association for the
Advancement of Colored
People
Legal Defense and Educational
Fund, Inc.
Philadelphia, PA

General Participants

Virginia Berg
U.S. Department of Education
Office of Migrant Education
Washington, DC

Catherine Bertini
Assistant Secretary for Food and
Consumer Services
U.S. Department of Agriculture
Washington, DC

Lea D. **Beshir**
District of Columbia Commission
of Public Health
Washington, DC

Susan Binder, M.D.
Centers for Disease Control
Atlanta, GA

Patrice **Birman**
U.S. General Accounting Office
Washington, DC

Kathleen Kirk Bishop, D.S.W.
Vermont Department of Social
Work
Burlington, VT

Lorine P. **Bizzell**
U.S. Department of Agriculture
Food and Nutrition Service
Atlanta, GA

Tara Blackcoon
Wisconsin Winnebago Health
Authority
Mauston, WI

Vicki Blackcoon
Wisconsin Winnebago Health
Authority
Mauston, WI

Randall Blackdeer
Wisconsin Winnebago Health
Authority
Mauston, WI

Heather Block
U.S. Department of Agriculture
Child Nutrition Service
Alexandria, VA

Joy E. **Blount**
Georgia Department of
Education
Atlanta, GA

Donna **Blum**
National Institutes of Health
Bethesda, MD

Stephanie Bordenick
National Institutes of Health
Rockville, MD

Mary **Ellen** Bradshaw, M.D.
Bureau of School Health Service
Washington, DC

Charlotte **Brantley**
Texas Department of Human
Services
Austin, TX

George **Brenneman**
U.S. Public Health Service
Rockville, MD

Patrick Bresette
Center for Public Policy Priorities
Austin, TX

Adrienne Brigmon
Head Start Bureau
Washington, DC

Robin Brocato, M.H.S.
Head Start Bureau
Washington, DC

Leigh Brown
Oklahoma State Department of
Health
Oklahoma City, OK

Linda Brown
Health Care Financing
Administration
Washington, DC

Scott Brown
U.S. Department of Education
Office of Special Education
Programs
Washington, DC

Marsha E. Butler, D.D.S., M.P.H.
Colgate-Palmolive Company
New York, NY

John A. Butterfield
President's Council on Physical
Fitness and Sports
Washington, DC

Ann G. **Cagigas**, R.N., IBCLC
Guaynabo, PR

Suzanne Camp
Greater Southeast Healthcare
System
Washington, DC

Mary M. Campbell
American Psychological
Association
Washington, DC

Rose Cardinal
Asthma and Allergy Foundation
Washington, DC

Mary Brecht Carpenter, R.N.,
M.P.H.
National Commission to Prevent
Infant Mortality
Washington, DC

Lorraine **Carrimon**
Wisconsin Winnebago Health
Authority
Mauston, WI

General Participants

Sylvia Carter
Head Start Bureau
College Park, MD

Sandra Carton
Head Start Bureau
Washington, DC

DonnaRae Castillo
National Research Service Award
Training Program
Rockville, MD

Jennifer M. Cernoch, Ph.D.
Santa Rosa Children's Hospital
San Antonio, TX

Gwen D. Chance
Texas Head Start Collaboration
Austin, TX

**Barbara E. Chandler, M.O.T.,
O.T.R.**
American Occupational Therapy
Association
Rockville, MD

Bruce R. Chelikowsky
Indian Health Service
Rockville, MD

Ann Chen
Nurses Association of the College
of Obstetricians and
Gynecologists
Washington, DC

Deborah Clark
National Immunization
Campaign
Washington, DC

Valencia Clarke
Association for the Care of
Children's Health
Bethesda, MD

Deborah Clendaniel, M.S.
Delaware Maternal and Child
Health Services
Dover, DE

Helen T. Closson
Elliot Health System
Manchester, NH

Beverly Coleman-Miller, M.D.
The BCM Group, Inc.
Washington, DC

Robert J. Collins
Indian Health Service
Rockville, MD

Donna L. Conforti
U.S. Department of Education
Washington, DC

Mary Ann Cooney
Manchester Health Department
Manchester, NH

Lori Cooper
Healthy Mothers, Healthy Babies
Washington, DC

Genevive W. Cornelius
U.S. Department of Education
Office of Elementary and
Secondary Education
Washington, DC

Anna Critz
U.S. Department of Education
Washington, DC

Nancy Cude
Arlington Early Intervention
Coordinating Council
Arlington, VA

Ronald Daly
U.S. Department of Agriculture
Extension Service
Washington, DC

Diane D'Angelo
RMC Research Corporation
Portsmouth, NH

Suzanne Danielson
Department of Health and
Hospitals
Baton Rouge, LA

Margaret (Peg) M. Davis
Governor's Planning Office
Harrisburg, PA

Robert E. Dawson
U.S. Public Health Service
Rockville, MD

Alberta Day
Wisconsin Winnebago Health
Authority
Mauston, WI

Mary Dale DeBore
Bethesda, MD

Chris DeGraw, M.D., M.P.H.
U.S. Department of Health and
Human Services
Office of the Assistant Secretary
of Health
Washington, DC

Debra Delgado
School Based Adolescent Health
Care Program
Washington, DC

Diana Denboba
U.S. Public Health Service
Rockville, MD

Sara Reed DePersio
Oklahoma Department of Health
Oklahoma City, OK

Julie DeSeyn
The Home and School Institute
Washington, DC

General Participants

Dee Dickehnan
Child Protection Program
Falls Church, VA

Patricia Divine-Hawkins
Head Start Bureau
Washington, DC

Clare M. Domenici
U.S. Department of Health and
Human Services
Washington, DC

Dana M. Dorf
U.S. Department of Agriculture
Food and Nutrition Service
Boston, MA

Laura Drake
Barbara Bush Foundation for
Family Literacy
New York, NY

M. Ann Drum, D.D.S., M.P.H.
Office of the Surgeon General
Washington, DC

Mary Jean Duckett
Health Care Financing
Administration
Baltimore, MD

B. Richmond Dudley, Jr.
General Services Administration
Washington, DC

John C. Duffy
U.S. Public Health Service
Rockville, MD

Janet Dumont
U.S. Public Health Service
Rockville, MD

Dennis Dunn
Growing Child
Lafayette, IN

Leslie Dunne
Healthy Mothers, Healthy Babies
Washington, DC

Eden Fisher Durbin
Y.M.C.A. of the U.S.A.
Washington, DC

Melanie Earl
Santa Rosa Children's Hospital
San Antonio, TX

Larry Edehnan
The Kennedy Institute
Baltimore, MD

Maurice J. Elias, Ph.D.
Rutgers University
New Brunswick, NJ

Gail Johnston Ellis
Epilepsy Foundation of America
Landover, MD

Ann Ellwood
Minnesota Early Learning Design
Minneapolis, MN

Martha Emerling
Schwartz Foundation
Mt. Laurel, NJ

LaRue Emmell
Montgomery County Health
Department
Norristown, PA

Lou Enoff
Social Security Administration
Baltimore, MD

Wiie L. Epps, Ph.D.
St. Clair County Head Start
Program
East St. Louis, IL

Bob Erbetta
U.S. Naval Reserve-Campaign
Drug Free America
Marblehead, MA

Alyson Escobar
U.S. Department of Agriculture
Hyattsville, MD

Juanita C. Evans, M.S.W.
U.S. Public Health Service
Rockville, MD

Nancy Evans
Manchester School District
Manchester, NH

Elizabeth Farquhar, Ph.D.
U.S. Department of Education
Office of the Undersecretary
Washington, DC

Herta B. Feely
National SAFE KIDS Campaign
Washington, DC

Janice Feld
Legislative Affairs Specialist
Alexandria, VA

Karen S. Fennell
American College of Nurse-
Midwives
Washington, DC

Sister Isolina Ferré
Easter Seals
Ponce, PR

M. J. Fingland
Office of the Surgeon General
Washington, DC

Marilyn J. Flood
Child Care Action Campaign
New York, NY

General Participants

Tony Fowler
U.S. Department of Education
Washington, DC

Amy Fox
American Academy of Pediatric
Dentistry
Chicago, IL

Harriette Fox
Fox Health Policy Consultants,
Inc.
Washington, DC

Clara L. French
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Amy Friedlander
U.S. General Accounting Office
Washington, DC

Robert G. Froehlke, M.D.
Office of the Surgeon General
Washington, DC

Robin S. Funston
U.S. Department of Health and
Human Services
Office of the Secretary
Washington, DC

Margaret Garikes
Office of the Surgeon General
Washington, DC

**Constance Garner, R.N.C.,
M.S.N., Ed.S.**
U.S. Department of Education
Office of Special Education
Programs
Washington, DC

Preston J. Garrison
United Way of America
Alexandria, VA

Karen T. Garthright
U.S. Department of Health and
Human Services
Food and Drug Administration
Rockville, MD

Kay Ghahremani
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Frankie Gibson
Head Start Bureau
Washington, DC

Barbara Gleason
America 2000
Washington, DC

Mike Golden
Maryland Department of Health
and Mental Hygiene
Baltimore, MD

Gloria Gonzalez
Office of the Surgeon General
Washington, DC

Nilda M. Gonzalez
Puerto Rico Easter Seals
San Juan, PR

Bill Gould
National Network of Self Help
Clearinghouses
Los Angeles, CA

Linda Graham
Children's Rehabilitation Service
Montgomery, AL

Holly Grason
Association of Maternal and
Child Health Programs
Washington, DC

Pamela Greenberg
National Association of Pediatric
Nurses and Practitioners
Washington, DC

Joan Greene
National Association of Pediatric
Nurses and Practitioners
Arnold, MD

Sarah M. Greene
Administration for Children,
Youth and Families
Alexandria, VA

Aido G. Gregory
Puerto Rico Department of
Health
Puerto Rico

Sue Greig, M.S., R.D.
American School Food Service
Association
Manhattan, KS

Jerry Griepentrog
Carson City, NV

Mark Grimes
American Academy of Pediatrics
Elk Grove Village, IL

Lucy Gritzmacher
Candlelighters Childhood
Cancer Foundation
Washington, DC

Virgil Gulker
Love, Inc.
Holland, MI

Lynn F. Gurkin
Department of Environment,
Health, and Natural Resources
Raleigh, NC

William H.J. Haffner, M.D.
Indian Health Service
Bethesda, MD

General Participants

Cynthia Haileselassie
U.S. Department of Health and
Human Services
Washington, DC

Barbara Hallman
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Janice Hamilton
JMH Communications
New York, NY

Anne L. Hansen
Michigan Department of
Education
Lansing, MI

Connie Hansen
Council of Community Services
of Roanoke
Roanoke, VA

Kirsten Hansen, M.Ed.
Georgetown University Child
Development Center
Washington, DC

**Robert G. Harmon, M.D.,
M.P.H.**
Health Resources and Services
Administration
Rockville, MD

Jackie Harrison, R.N.
Children's Hospital
New Orleans, LA

Max Harrison
American School Food Service
Association
Alexandria, VA

Edith Harvey
U.S. Department of Education
Office of Migrant Education
Washington, DC

William Haskins
National Urban League
New York, NY

Laura Havens
March of Dimes
Washington, DC

Ethel Hawkins
District of Columbia General
Hospital
Washington, DC

**Barbara Heiser, R.N., B.S.N.,
IBCLC**
La Leche League International
Franklin Park, IL

Michael H. Henrichs, Ph.D.
Kids Adjusting Through
Support, Inc.
Rochester, NY

**O. Marie Henry, R.N.,
DNSC, FAAN**
Office of the Surgeon General
Washington, DC

Victoria Hertel
American School Health
Association
Littleton, CO

Catherine A. Hess, MSW
American Public Health
Association
Washington, DC

Laurie Hicherson
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Grant Higginson, M.D., M.P.H.
Office of Health Services
Portland, OR

Donna Hines
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Sandra L. Hofferth, Ph.D.
The Urban Institute
Washington, DC

Patrick F. Hogan
U.S. Department of Education
Office of Migrant Education
Washington, DC

Joan Holloway
Division of Special Populations
Program Development
Rockville, MD

Silvia Holschneider
National Health Education
Consortium
Washington, DC

Jerry K. Hood
U.S. Public Health Service
Rockville, MD

Beverly J. Hoover
American Red Cross
Washington, DC

Wade F. Horn, Ph.D.
Administration for Children,
Youth and Families
Washington, DC

Karen Horne
South Carolina Governor's
Office
Columbia, SC

Alice M. Horowitz
National Institutes of Health
Bethesda, MD

Vernon N. Houk, M.D.
Centers for Disease Control
Atlanta, GA

General Participants

Frances Howard
National Library of Medicine
Rockville, MD

Judy Hudgins
Virginia Department of
Education
Richmond, VA

Louise Hunt, R.N., B.S.N.
U.S. Public Health Service
Rockville, MD

Vince L. Hutchins
U.S. Public Health Service
Rockville, MD

Michael T. Hymn, Ph.D.
University of Wisconsin-
Milwaukee
Milwaukee, WI

Darla Ideus
Center on Budget and Policy
Priority
Washington, DC

Roger Iron Cloud
Head Start Bureau
Washington, DC

Angeles Lopez Isales
Departamento de Education de
Puerto Rico
Hato Rey, PR

Brenda James-Pitt
Montgomery County Health
Department
Norristown, PA

Mary A. Jansen, Ph.D.
U.S. Department of Health and
Human Services
Alcohol, Drug Abuse and Mental
Health Administration
Rockville, MD

David Johnsen
Case Western Reserve University
Cleveland, OH

Beverly H. Johnson
Association for the Care of
Children's Health
Bethesda, MD

Dr. Jerry M. Johnson
U.S. Coast Guard
Washington, DC

Richard H. Johnson, ACSW
Head Start Bureau
Washington, DC

Susan Johnson
Texas - Office of the Governor
Austin, TX

Dennis Jolley
Office of the Surgeon General
Washington, DC

Bertha Jones
U.S. Department of Housing and
Urban Development
Washington, DC

Cami Jones
Texas Education Agency
Austin, TX

Deborah Jones
New Jersey State WIC Program
Trenton, NJ

Linda Jupin
U.S. Department of Agriculture
Food and Nutrition Service
Washington, DC

Marta Kealey
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Woodie Kessel
U.S. Public Health Service
Washington, DC

Arlene Kiely
Association for the Care of
Children's Health
Bethesda, MD

Stephen King
Agency for Health Care Policy
and Research
Rockville, MD

Randy Kingsley
U.S. Department of Education
Washington, DC

Regina L. Kinnard
U.S. Department of Education
Washington, DC

Ellen Eliason Kisker, Ph.D.
Mathematica Policy Research,
Inc.
Princeton, NJ

Nancy Kleckner
Growing Child, Growing Parent
Lafayette, IN

Jean Klinge
U.S. Department of Education
Washington, DC

Jane Kratovil
Council of Chief State School
Officers
Washington, DC

Stephen H. Kreimer
National School Health
Education Coalition
Washington, DC

Mary A. Krickus
American School Food Service
Association
Alexandria, VA

General Participants

Heidi Kurtz
American Federation of
Teachers
Washington, DC

Hanns Kuttner
Office of Policy Development
The White House
Washington, DC

Leslie Lanham
Children's Defense Fund-Texas
Austin, TX

Cheryl LaPointe
U.S. Public Health Service
Rockville, MD

Georgianna Larson
Pathfinder Resources, Inc.
St. Paul, MN

Kristen Larson
U.S. Department of Health and
Human Services
Washington, DC

Dora L. Lasanta
Departamento de Education de
Puerto Rico
Bayamón, PR

Bill Latimer
North Carolina Governor's
Office
Washington, DC

Charles LaVallee
Western Pennsylvania Caring
Foundation, Inc.
Pittsburgh, PA

Donna F. LaVallee
New Visions for Newport County
Newport, RI

Jean E. Lazar
U.S. Public Health Service
Rockville, MD

Rice C. Leach, M.D.
Office of the Surgeon General
Rockville, MD

Brenda Leath
National Health/Education
Consortium
Washington, DC

Meg Leavy
University of Maryland
College Park, MD

Alice Lenihan, R.D.
North Carolina State
Department of Environment,
Health and Natural Resources
Raleigh, NC

Donna Leno
Indian Health Service
Rockville, MD

Susan Lenox Goldman
State of New Jersey
Trenton, NJ

Ann W. Lewin
The National Learning Center
Washington, DC

Helen D. Lilly, Ph.D.
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Lauren Long
Columbia, MD

Thomas J. Long, Ph.D.
Long and Associates
Bethesda, MD

John T. MacDonald, Ph.D.
U.S. Department of Education
Assistant Secretary of Education
for Elementary and Secondary
Education
Washington, DC

Thomas C. MacMichael
Comprehensive Health
Investment Project (CHIP)
Replication - Total Action
Against Poverty (TAP)
Roanoke, VA

Edward Madigan
Secretary of Agriculture
Washington, DC

Patricia Mail
U.S. Public Health Service
Rockville, MD

Lani Smith Majer
Anne Arundel County Health
Department
Annapolis, MD

Pamela Mangu
Georgetown University
Washington, DC

Howard Manly
Deputy Commissioner of Public
Health
Washington, DC

James Manning
U.S. Department of Education
Washington, DC

Carolyn Marsh
Arkansas Children's Hospital
Little Rock, AR

Judy Martin
East Kentucky Child Care
Coalition
Annville, KY

José Martinez
Puerto Rico Department of
Health
Puerto Rico

General Participants

Julian Martinez
U.S. Department of Education
Washington DC

James O. Mason, M.D.
Assistant Secretary for Health
U.S. Department of Health and
Human Services
Washington, DC

Jimmy Mason
Office of the Surgeon General
Washington, DC

Debbie Massey
U.S. Department of Agriculture
Food and Nutrition Service
McLean, VA

Bijoy Mathew
Association of Maternal and
Child Health Programs
Washington, DC

Lisa Matras
Office of the Surgeon General
Washington, DC

William P. Matson
Commonwealth of the
Northern Mariana Islands
Public School System
Saipan, MP

Thurma McCann, M.D., M.P.H.
Office of Healthy Start
Rockville, MD

Mark C. McClary
National Association of WIC
Directors
Washington, DC

Phyllis McClure
National Association for the
Advancement of Colored
People
Legal Defense and Educational
Fund, Inc.
Washington, DC

Beverly McConnell
Michigan Department of Public
Health
Detroit, MI

Pat McCulla
Children's Hospice International
Alexandria, VA

Sandra J. McElhaney, M.A.
National Mental Health
Association
Alexandria, VA

Dr. Alice McGill
U.S. Navy Personal Excellence
Partnership Program
Washington, DC

Mary McGonigel
Association for the Care of
Children's Health
Bethesda, MD

Dennis D. McIlhenny
Charles Webb Easter Seals
Center Parent Association
Mt. Pleasant, SC

Patricia A. McKee, ED
U.S. Department of Education
Office of Elementary and
Secondary Education
Washington, DC

Connie McLendon
Texas Association for the Gifted
and Talented
Round Rock, TX

Elizabeth McManis
Barbara Bush Foundation for
Family Literacy
Washington, DC

Michelle H. Metts
Cabinet for Human Resources
Frankfort, KY

Angela D. Mickalide
National SAFE KIDS Campaign
Washington, DC

Elizabeth Milder-Beh
Pennsylvania Governor's Office
Harrisburg, PA

Christine Miller
U.S. Department of Education
Washington, DC

Howard T. Miller
Glenn Dale Early Childhood
Center
Glendale, MD

Robert C. Miller
Todd County Schools
Mission, SD

June Miion
National Association of
Elementary School Principals
Alexandria, VA

Claudette Mitchell, M.B.A.
U.S. Public Health Service
Rockville, MD

Winnie Mitchell
Office of the Surgeon General
Washington, DC

Evelyn Moch
D.O.T. Day Care, Inc.
Washington, DC

William Modzeleski
U.S. Department of Education
Washington, DC

Eileen L. Moe, CSW-ACP
Texas Health Department
Austin, TX

Linda G. Morra
U.S. General Accounting Office
Washington, DC

General Participants

Claudia Morris
Healthy Mothers, Healthy Babies
Washington, DC

José Muñoz
National Coalition of Hispanic
Health and Human Services
Organizations
Washington, DC

Martha Naismith
Johnson & Johnson HMI
Washington, DC

Carol Nasworthy
Texas Work and Family
Clearinghouse
Austin, TX

Pam Navarro
National Institutes of Health
Germantown, MD

Richard P. Nelson, M.D.
Child Health Specialty Clinics
Iowa City, IA

Liz Newhouse
Texas Respite Resource Network
San Antonio, TX

Mary Nichols
Sigma Theta Tau
Clifton, VA

Erik Nielsen
American Occupational Therapy
Association
Rockville, MD

Lulu Mae Nix, Ed.D.
National Institute for Integrated
Family Services
Camden, NJ

Julie M. Novak
Alabama Department of Public
Health
Montgomery, AL

Jackie Noyes
American Academy of Pediatrics
Washington, DC

Christine Nye
Health Care Financing
Administration
Baltimore, MD

Diane O'Connor
Governor's Office for Children,
Youth, and Families
Baltimore, MD

Godfrey P. Oakley, Jr., M.D.
Centers for Disease Control
Atlanta, GA

William Oliver
PRIDE Parent Training
Marietta, GA

Sally Olsen
Santa Rosa Children's Hospital
San Antonio, TX

Walter A. Orenstein, M.D.
Centers for Disease Control
Atlanta, GA

Belinda Ortega
Ysleta Del Sur Pueblo
El Paso, TX

JoAnne Owens-Nauslar
Nebraska Department of
Education
Lincoln, NE

Miriam Padilla, M.D.
Rockville, MD

Deborah Parham
Special Initiative, Policy and
Evaluation Branch
Rockville, MD

Barbara Park
American Dental Association
Chicago, IL

Steven Parker, M.D.
Boston City Hospital
Boston, MA

Sandra Parks-Trusz, Ph.D.
Epilepsy Foundation of America
Landover, MD

John Patrick Passino
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Lori Pastro
U.S. Department of Health and
Human Services
Washington, DC

Anne L. Pavlich, R.N.
U.S. Consumer Product Safety
Commission
Bethesda, MD

Robyn J. Payne
Girl Scouts of the U.S.A.
New York, NY

Gloria Pereira
Frederick County Head Start
Frederick, MD

Steve **Permison, M.D.**
Indian Health Service
Washington, DC

Hilma M. Persson
Woodbridge, VA

Alwin K. Peterson
Michigan Department of
Public Health
Lansing, MI

Sharon L. Philip
Alexandria City Health
Department
Alexandria, VA

Patricia Phipps
Institute for Child Care
Professionals
Houston, TX

Patricia Place
Natural Academy of Sciences
Washington, DC

Deborah Fells Pleasants
Washington DC Public Schools
Washington, DC

Julia Plotnick, R.N.C., M.P.H.
U.S. Public Health Service
Rockville, MD

Michele A. Plutro, Ed.D.
Head Start Bureau
Washington, DC

Betty S. Poehhnan
National School Boards
Association
Alexandria, VA

Susan Poisson, M.A.
Reginald S. Lourie Center for
Infants and Young Children of
Maryland and Virginia
Rockville, MD

Florene Stewart Poyadue
Parents Helping Parents
San Jose, CA

E. Ann Prendergast
U.S. Public Health Service
Rockville, MD

Theressa Price, R.N.
Jackson-Hinds Comprehensive
Health Center
Jackson, MS

Daniel Puntillo, Jr.
Middle Earth
Somerville, NJ

Kathryn F. Purnell
South Carolina Department of
Health and Environmental
Control
Columbia, SC

James F. Quilty, Jr., M.D.
Ohio Department of Health
Columbus, OH

Craig T. Ramey, Ph.D.
University of Alabama-
Birmingham
Birmingham, AL

Arnold D. Ramiiez
Phoenix Human Services
Head Start
Phoenix, AZ

Maria Rapuano
Alliance To End Childhood Lead
Poisoning
Washington, DC

Karl A. Reis
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Letitia Rennings, M.S.
U.S. Department of Education
Washington, DC

Judith Ressallat
National Association of School
Nurses, Inc.
Washington, DC

Christopher Rigaux
National Center for Education in
Maternal and Child Health
Washington, DC

Suzanne Ripley
National Information Center for
Children and Youth with
Disabilities
McLean, VA

Lourdes A. Rivera
Children's Defense Fund
Washington, DC

Latricia Robertson
U.S. Public Health Service
Rockville, MD

Diana Robinson
Center for Successful Child
Development
Chicago, IL

Cindy Rojas Rodriguez
Southwest Educational
Development Laboratory
Austin, TX

Mark L. Rosenberg, M.D., M.P.P.
Centers for Disease Control
Atlanta, GA

Judith Rosenberg, LCSW
Support Group Training Project
Berkeley, CA

John P. Rossetti
U.S. Public Health Service
Rockville, MD

Paula Russell
Texas Health Department
Austin, TX

Jesus Saavedra, M.D.
U.S. Public Health Service
Washington, DC

**Patricia A. Salomon, M.D.,
C.M.O.**
U.S. Department of Health and
Human Services
Rockville, MD

General Participants

Helen Scheirbeck
Head Start Bureau
Washington, DC

Diane Schilder
U.S. General Accounting Office
Washington, DC

Elizabeth Schmidt
Office of the Surgeon General
Washington, DC

George A. Schmidt, Ph.D.
Florida State Interagency Office
of Disability Prevention
Tallahassee, FL

William Sciarillo
Maryland State Health
Department
Baltimore, MD

Mary A. Scoblic, R.N., M.N.
Michigan Department of
Public Health
Lansing, MI

Elaine L. Scott
Capitol Children's Museum
Washington, DC

Maureen Seller
National Center for Education in
Maternal and Child Health
Washington, DC

Fadrienne Sessions
Jackson Hines Comprehensive
Health Center
Jackson, MS

Paula M. Sheahan
National Center for Education in
Maternal and Child Health
Washington, DC

Steven P. Shelov, M.D.
Albert Einstein College of
Medicine
Bronx, NY

Joy Shelton
Delta College
University Center, MI

Bill Shepardson
Council of Chief State School
Officers
Washington, DC

Phyllis J. Siderits
Institute for Child Health Policy
Gainesville, FL

Tom Slatton, Ph.D.
Texas Department of Human
Resources
Amarillo, TX

Elizabeth Sloan
Elliot Health Systems/Elliot
Hospital
Manchester, NH

Allen N. Smith
Head Start Bureau
Washington, DC

Becky J. Smith, Ph.D.
Association for the Advancement
of Health Education
Reston, VA

Marnie Smith
Peyser Associates
Washington, DC

Joanne Smogor
Manchester School District
Manchester, NH

John A. Snowden
Capitol Children's Museum
Washington, DC

Carolyn Snyder
U.S. Department of Education
Washington, DC

Sherrie Socha
Governor's Development
Disability Council
Omaha, NE

Denise Sofka
U.S. Public Health Service
Rockville, MD

Marian Sokol, Ph.D.
The Children's Hospital
Ambulatory Care Center
San Antonio, TX

Benita Somerfield
Barbara Bush Foundation for
Family Literacy
New York, NY

Lydia Soto-Torres, M.D., M.P.H.
Office of the Surgeon General
Washington, DC

Georgeline Sparks
Indian Health Service
Rockville, MD

Lynn Spector
U.S. Public Health Service
Rockville, MD

Leslie Stablein
Arlington County Department of
Human Services
Arlington, VA

Irene Steibing
Maryland Department of Human
Resources
Baltimore, MD

Walter Steidle, Ph.D.
U.S. Department of Education
Washington, DC

General Participants

John Steiudorf

Wisconsin Winnebago Health
Authority
Mauston, WI

Delores Stewart

U.S. Department of Agriculture
Food and Nutrition Service
Trenton, NJ

Dianne Stewart

Center for Public Policy Priorities
Austin, TX

Joyce P. Stines

Appalachian State University
Boone, NC

Rosalie Streett

Parent Action
Baltimore, MD

Ann P. Streissguth, Ph.D.

University of Washington School
of Medicine
Seattle, WA

Nancy Striffler

Georgetown University Child
Development Center
Washington, DC

Phyllis Stubbs

U.S. Public Health Service
Rockville, MD

Caudace Sullivan

National Association of State
Boards of Education
Alexandria, VA

Louis Sullivan, M.D.

Secretary of Health and
Human Services
Washington, DC

Sherlie Svestka

U.S. General Accounting Office
Washington, DC

Lisa M. Tate

American Academy of Pediatrics
Washington, DC

Stephen B. Thacker, M.D., M.Sc.

Centers for Disease Control
Atlanta, GA

Carolyn Thiel

U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Josie Thomas

Association for the Care of
Children's Health
Bethesda, MD

Lucy A. Thompson

District of Columbia General
Hospital
Washington, DC

Claudia Thorue

Greater Southeast Healthcare
System
Washington, DC

Janet Tognetti

U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Geraldine Tompkins

WIC State Agency
Washington, DC

Debra Jean Torrez

Ysleta Del Sur Pueblo
El Paso, TX

Carol Treen

Manchester School District
Manchester, NH

Lori Tremmel

American Public Health
Association
Washington, DC

Elizabeth Tuckermanty

U.S. Department of Agriculture
Nutrition Extension Service
Washington, DC

Leticia Ubiuas, M.D.

U.S. Public Health Service
Alexandria, VA

Jeuifer Van Deusen

Maine Department of Education
Augusta, ME

Nancy Van Doren

The Travelers Companies
Foundation
Hartford, CT

Kaye Vander Ven

U.S. Public Health Service
Alexandria, VA

Karen VanLandeghem

National School Health
Education Coalition
Washington, DC

Peter K. Vaslow

Institute for the Enhancement of
Family Development
Bethesda, MD

Dr. Draga Vesseliuovitch

University of Chicago
Chicago, IL

Virginia View

National Center for Clinical
Infants Program
Arlington, VA

Amin Wahab

Community Development
Institute
Lakewood, CO

General Participants

Elayne Walker
National Association of
Community Health Centers
Washington, DC

Mary C. Wallace
U.S. Department of Health and
Human Services
Food and Drug Administration
Rockville, MD

Janet Wallinder
Multnomah County Health
Department
Portland, OR

Megan Walline
Department of Justice
Washington, DC

Sharon Walsh
Burke, VA

Gailya P. Walter
Centers for Disease Control
Washington, DC

Miie Waterman
National Parent-Teacher
Association
Mentor, OH

Mary Jo Waters
Love, Inc.
Holland, MI

C. J. Wellington, M.D.
Children with Special Health
Care Needs
Washington, DC

Valerie Ahn Welsh
U.S. Public Health Service
Washington, DC

Jerry West
National Center for Educational
Statistics
Washington, DC

Beth Wetherbee
Delaware Division of Public
Health
Dover, DE

Debra Whitford
U.S. Department of Agriculture
Food and Nutrition Service
Alexandria, VA

Clarissa Whittenberg
National Institutes of Health
Washington, DC

Steve Wickizer, R.Ph.
Office of the Surgeon General
Washington, DC

Lori Wicks
Fox Health Policy Consultants,
Inc.
Washington, DC

Sally Wilberding
National Institute for Dental
Research
Bethesda, MD

Barbara A. Willer, Ph.D.
National Association for the
Education of Young Children
Washington, DC

A. Kenton Williams, Ed.D.
Head Start Bureau
Washington, DC

J. Terry Williams, R.D., M.P.H.
Wyoming Department of Health
Cheyenne, WY

Kim Williams
Arkansas Children's Hospital
Little Rock, AR

Barbara Wells Willis
U.S. Department of Agriculture
Washington, DC

Lorna Wilson, R.N., M.S.P.H.
Missouri Department of Health
Jefferson City, MO

**Modena E.H. Wilson, M.P.H.,
M.D.**
Johns Hopkins University
Baltimore, MD

Shirley I. Wiion
Commission on Public Health
Silver Spring, MD

Susan Winingar
U.S. Department of Education
Washington, DC

Mildred M. Winter, M.Ed.
Parents as Teachers National
Center
St. Louis, MO

Bonnie Wise
United Planning Organization
Washington, DC

Frances O. Witt
Maryland State Department of
Education
Baltimore, MD

Kelly Woods
JMH Communications
New York, NY

Beverly Wright
U.S. Public Health Service
Rockville, MD

Sharon E. Yandian
Head Start Bureau
Washington, DC

Dorothy M. Yonemitsu
San Diego Imperial
Developmental Services, Inc.
and the Union of Pan Asian
Communities
San Diego, CA

General Participants

Lenore Zedosky

West Virginia Department of
Education
Charleston, WV

Edward Zigler, Ph.D.

Yale University
New Haven, CT

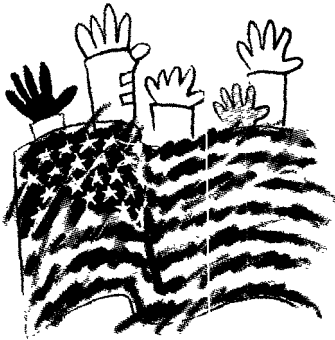
**Advisory
Group**

Appendix B

Advisory Group

The Surgeon General's Conference

HEALTHY CHILDREN



Ready to Learn

The Critical Role of Parents

Washington, DC

February 9-12, 1992

William R. Archer III, M.D.

Deputy Assistant Secretary for Population Affairs
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
Room 736E
200 Independence Avenue, SW
Washington, DC 20201

Jane Baird

Deputy Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
Room 410E
200 Independence Avenue, SW
Washington, DC 20201

Daniel Bonner

Deputy Assistant Secretary for Elementary and
Secondary Education
U.S. Department of Education
Room 2181, FOB 6, Mailstop 6100
400 Maryland Avenue, SW
Washington, DC 20202

Richard Chambers

Director, Intergovernmental Affairs Office
Health Care Financing Administration
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
Room 410B
200 Independence Avenue, SW
Washington, DC 20201

Chris DeGraw, M.D., M.P.H.

Coordinator for the Children and Schools Program
Office of Disease Prevention and Health Promotion
U.S. Public Health Service
U.S. Department of Health and Human Services
Switzer Building, Room 2132
330 C Street, SW
Washington, DC 20201

Marilyn H. Gaston, M.D.

Director, Bureau of Health Care Delivery and Assistance
U.S. Public Health Service
U.S. Department of Health and Human Services
Parklawn Building, Room 7-05
5600 Fishers Lane
Rockville, MD 20857

Alan Hinman, M.D., M.P.H.
Director, Center for Prevention Services
Centers for Disease Control
U.S. Public Health Service
U.S. Department of Health and Human Services
1600 Clifton Road, Mail Stop E07
Atlanta, GA 30333

Wade Horn, Ph.D.
Commissioner, Administration for Children, Youth
and Families
Administration for Children and Families
U.S. Department of Health and Human Services
Switzer Building, Room 2026
330 C Street, SW
Washington, DC 20201

Vince L. Hutchins, Ph.D.
Acting Director, Maternal and Child Health Bureau
Health Resources and Services Administration
U.S. Public Health Service
U.S. Department of Health and Human Services
Parklawn Building, Room 9-03
5600 Fishers Lane
Rockville, MD 20857

Elaine Johnson, Ph.D.
Director, Office for Substance Abuse Prevention
Alcohol, Drug Abuse and Mental Health
Administration
Rockwall II, Room 9D-10
5600 Fishers Lane
Rockville, MD 20857

Paul Johnson, Ph.D.
Office of Health Planning and Evaluation
Office of the Assistant Secretary for Health
U.S. Public Health Service
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
Room 740G
200 Independence Avenue, SW
Washington, DC 20201

Hanns Kuttner
Associate Director for Health and Social Services
Policy
Old Executive Office Building, Room 219
Washington, DC 20500

John T. MacDonald, Ph.D.
Assistant Secretary for Elementary and Secondary
Education
U.S. Department of Education
400 Maryland Avenue, SW
Room 2189
Washington, DC 20202

Rae Nelson
Deputy Associate Director for Education and Drug Policy
Old Executive Office Building, Room 218
Washington, DC 20500

Jeffrey Rosenberg
Special Assistant to the Commissioner
Administration on Children, Youth, and Families
Administration for Children and Families
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

David Rostetter
Coordinator, School Readiness Initiative
Office of the Assistant Secretary for Planning and
Evaluation
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
Room 415F
200 Independence Avenue, SW
Washington, DC 20201

Stephen J. Sepe, Ph.D., M.P.H.
National Vaccine Program Coordinator
Division of Immunization
National Center for Prevention Services
Centers for Disease Control
U.S. Department of Health and Human Services
1600 Clifton Road, Mail Stop E-07
Atlanta, GA 30333

Carolyn Snyder
Confidential Assistant to the Assistant Secretary for
Elementary and Secondary Education
U.S. Department of Education
Room 2181, FOB 6, Mailstop 6100
400 Maryland Avenue, SW
Washington, DC 20202

W. Craig Vanderwagen, M.D.
Acting Associate Director, Office of Health Programs
Indian Health Service
U.S. Public Health Service
U.S. Department of Health and Human Services
Parklawn Building, Room 6A-55
5600 Fishers Lane
Rockville, MD 20857

Ronald J. Vogel
Director, Supplemental Food Programs
Food and Nutrition Service
U.S. Department of Agriculture
3101 Park Center Drive, Room 1017
Alexandria, VA 22302

Gaila Walters
Program Officer
Office on Smoking and Health
U.S. Department of Health and Human Services
Switzer Building, Room 1229
330 C Street, SW
Washington, DC 20201

Valerie Ahn Welsh
Office of Health Planning and Evaluation
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
Room 740G
200 Independence Avenue, SW
Washington, DC 20201

Paul Wise, M.D., M.P.H.
Maternal and Child Care Health Expert
Joint Program in Neonatology
221 Longwood Avenue, 5th Floor
Boston, MA 02115

Sumner Yaffe, M.D.
Director, Center for Research for Mothers and Children
National Institute for Child Health and Human Development
National Institutes of Health
U.S. Public Health Service
U.S. Department of Health and Human Services
Executive Plaza North, Room 643
9000 Rockville Pike
Bethesda, MD 20892

§

Office of the Surgeon General
U.S. Public Health Service
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

M. Ann Drum, D.D.S., M.P.H.
Special Assistant for Program Activities

M.J. Fingland
Director of Public Affairs

Margaret Garikes
Executive Assistant

Louise Hunt, R.N., B.S.N.
Assistant to the Chief of Staff

Rice C. Leach, M.D.
Chief of Staff

Lisa Matras
Special Assistant

Winnie Mitchell
Policy Coordinator for AIDS and Underage Drinking

Elizabeth Schmidt
Director of Communications

Lydia Soto-Torres, M.D., M.P.H.
Policy Coordinator for Women's Health

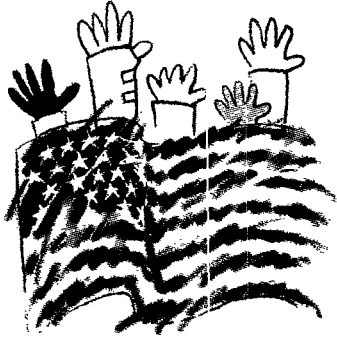
Planning Committee

Appendix C

Planning Committee

The Surgeon General's Conference

HEALTHY CHILDREN



--- Ready to Learn ---

The Critical Role of Parents

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Robin Brocato, M.H.S.
Health Specialist
Head Start Bureau
U.S. Department of Health and Human Services
P.O. Box 1182
Washington, DC 20513

Chris DeGraw, M.D., M.P.H.
Coordinator of Children and Schools Program
Office of Disease Prevention and Health Promotion
Office of the Assistant Secretary of Health
U.S. Department of Health and Human Services
2132 Switzer Building
330 C Street, SW
Washington, DC 20201

Diana Denboba
Public Health Analyst
Habilitative Services Branch
Maternal and Child Health Bureau
U.S. Public Health Service
U.S. Department of Health and Human Services
Parklawn Building, Room 18A-18
5600 Fishers Lane
Rockville, MD 20857

M. Ann Drum, D.D.S., M.P.H.
Special Assistant for Program Activities
Office of the Surgeon General
U.S. Public Health Service
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
Room 718E
200 Independence Avenue, SW
Washington, DC 20201

Robert G. Froehlke, M.D.
Special Assistant to the Surgeon General
Office of the Surgeon General
U.S. Public Health Service
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
Room 718E
200 Independence Avenue, SW
Washington, DC 20201

Louise Hunt, R.N., B.S.N.
Assistant to the Chief of Staff
Office of the Surgeon General
U.S. Public Health Service
U.S. Department of Health and Human Services
Parklawn Building, Room 18-67
5600 Fishers Lane
Rockville, MD 20857

Linda Jupin
Food Program Specialist
Food and Nutrition Service
U.S. Department of Agriculture
3101 Park Center Drive, Room 540
Alexandria, VA 22302

Marta Kealy
Food Program Specialist
Food and Nutrition Service
U.S. Department of Agriculture
3101 Park Center Drive, Room 540
Alexandria, VA 22302

Miriam A. Kelly, Ph.D.
Project Officer
Center for Medical Effectiveness Research
Agency for Health Care Policy and Research
U.S. Public Health Service
U.S. Department of Health and Human Services
6001 Montrose Road, Suite 704
Rockville, MD 20852

Dushanka V. Kleinman, D.D.S., M.Sc.D.
Deputy Director
National Institute of Dental Research
National Institutes of Health
U.S. Public Health Service
U.S. Department of Health and Human Services
Building 31, Room 2C39
9000 Rockville Pike
Bethesda, MD 20892

Jean Klinge
Special Assistant to the Director of Compensatory
Education Programs
U.S. Department of Education
400 Maryland Avenue, SW, Room 2043
Washington, DC 20202

Rice C. Leach, M.D.
Chief of Staff
Office of the Surgeon General
U.S. Public Health Service
U.S. Department of Health and Human Services
Parklawn Building, Room 18-67
5600 Fishers Lane
Rockville, MD 20857

Patricia Mail
Public Health Analyst
Faculty Development Program
National Institute on Alcohol Abuse and Alcoholism
U.S. Public Health Service
U.S. Department of Health and Human Services
Parklawn Building, Room 14C-20
5600 Fishers Lane
Rockville, MD 20857

Pamela B. Mangu, M.A.
Early Childhood Specialist
National Center for Education and Maternal and
Child Health
Georgetown University
38th and R Streets, NW
Washington, DC 20057

Lisa Matras
Special Assistant
Office of Surgeon General
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
Room 718E
200 Independence Ave., SW
Washington, DC 20201

Julia Plotnick, R.N.C., M.P.H.
Chief Nurse
U.S. Public Health Service
Maternal and Child Health Bureau
U.S. Department of Health and Human Services
Parklawn Building, Room 18A-19
5600 Fishers Lane
Rockville, MD 20857

Carolyn Snyder
Confidential Assistant to the Assistant Secretary for
Elementary and Secondary Education
U.S. Department of Education
400 Maryland Avenue, SW
FOB 6, Room 2189
Washington, DC 20202

Josie Thomas
Family Networking Coordinator
Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814

Valerie Ahn Welsh
Senior Program Analyst
Office of Health Planning and Evaluation
U.S. Public Health Service
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
Room 740G
200 Independence Avenue, SW
Washington, DC 20201

Appendix D

Agenda at a Glance

Agenda at a Glance

Sunday, February 9

2:00 - 6:00
Registration

(Registration
8:00 - 5:30 each
day of the
Conference)

3:00 - 4:00 State Parent Delegate
Regional Meetings

5:00 - 7:00 Surgeon General's
Reception Honoring America's
Families

Monday, February 10

8:00 - 9:00 Opening Ceremonies

Joint Service Color Guard and Singers West

Invocation

Reverend Jeffrey Jerimah

*Pastor of Fourth Presbyterian Church
Bethesda, Maryland*

Welcome

Dr. Louis W. Sullivan

Secretary of Health and Human Services

Charge to Participants

Dr. Antonia C. Novello

Surgeon General

9:00 - 9:30 Break

Monday, February 10 (continued)

9:30 - 10:40 Concurrent Panel Sessions

Panel 2A—Healthy Children Ready to Learn:
What Are the Roles of Parents, Educators, Health
Professionals, and the Community?

Panel 2B—Special Issues that Impact Children
and Families: Substance Abuse, HIV, and
Violence

10:45 - 1:15

Parent
Work
Groups

*Lunch During
Work Group*

10:45 - 12:00

Concurrent Panel Sessions

Panel 1A—Early Childhood Issues
That Affect School Readiness
and Health

Panel 1B—Helping Families Get
Services: Some New Approaches

12:00 - 1:15 Luncheon Speaker

Dr. Willie Epps

1:20 - 1:50 Security Check

for President's Keynote Address

2:00 - 2:30 Keynote Address

George H. Bush

President of the United States of America

2:30 Break

2:30 - 5:30
Exhibits Open

4:00 - 5:00
Workshops 1-14

Everyone in State Parent Delegates Participants

Tuesday, February 11

8:30 - 9:00 Keynote Speech

Edward Madigan
Secretary of Agriculture

9:00 - 9:15 Break

9:15 - 12:15 Parent Work Groups

*Lunch During
Work Group*

**9:30 - 10:45
Concurrent Panel Sessions**
Panel 3A—Disabilities
**Panel 3B—Exploring Comprehensive
Health and Education Models for
Young Children**

10:45 - 11:00 Break

**11:00 - 12:30
Concurrent Panel Sessions**
**Panel 4A—Children With Special
Health Care Needs: Lessons
Learned**
**Panel 4B—Parenting: The Critical
Role**

12:30 - 3:30 Parent Work Groups

12:30 - 2:00 Lunch

**2:00 - 3:30
Concurrent Panel Sessions**
**Panel 5A—Child Care: Two
Perspectives**
**Panel 5B—Healthy Start, Head
Start, Even Start and WIC:
Integrating Health Education and
Social Service Programs**

3:30 Break

**3:30 - 5:30
Exhibits Open**

**4:00 - 5:00
Workshops 15-28**

Wednesday, February 12

8:30 - 9:00 Keynote Speech

Lamar Alexander
Secretary of Education

9:00 - 9:10 Speech

Roger B. Porter
*Assistant to the President for Economic and
Domestic Policy*

9:10 - 10:30 Findings of Parent Work Groups

10:30 - 11:45 Responder Panel

11:45 - 12:15 Meeting Summary

Dr. Antonia C. Novello
Surgeon General

Drug-Free Children: Parents Speak Out!

**Monday, February 10 ■ Tuesday, February 11
4:00 - 5:00**

We invite the parents to attend an open forum to share your views on a variety of topics related to raising drug-free children. A panel of representatives from the Department of Education and the Department of Health and Human Services will be present to hear your comments and answer questions about topics such as:

- ✓ What do children from birth to age seven need to know about drug prevention?
- ✓ How does drug use affect the lives of young children?
- ✓ How can parents prepare children to lead drug-free lives?
- ✓ How can schools and communities help?
- ✓ What preschool and early elementary programs include drug prevention?
- ✓ How important are drug education curricula for preschool and early elementary school children?

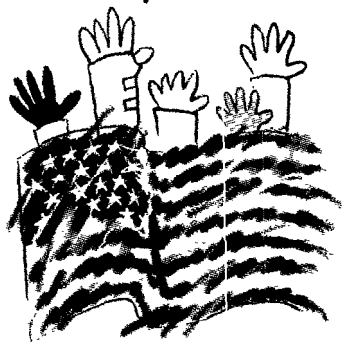
Appendix 3

Facilitators and Recorders

Facilitators

The Surgeon General's Conference

HEALTHY CHILDREN



Ready to Learn

The Critical Role of Parents

Washington, DC

February 9-12, 1992

Robert E. Alexander
Migrant Education
U.S. Department of Education
400 Maryland Avenue, SW
FOB 6, Room 2025
Washington, DC 20202

Robert W. Amler, M.D., M.S.
Agency for Toxic Substances and Disease Registry
Centers for Disease Control
U.S. Public Health Service
U.S. Department of Health and Human Services
1600 Clifton Road, NE
Mailstop E31
Atlanta, GA 30333

Sandy Bastone
Office of Analysis and Education
Food and Nutrition Service
U.S. Department of Agriculture
3101 Park Center Drive, Room 214
Alexandria, VA 22302

Virginia Berg
Migrant Education
U.S. Department of Education
400 Maryland Avenue, SW
FOB 6, Room 2025
Washington, DC 20202

Sylvia Carter
Head Start, Region 3, Resource Center
University of Maryland
University College
University Boulevard at Aldephi Road
College Park, MD 20742

Larry Edelman
Project Coordinator, The Kennedy Institute
Project Copernicus
Department of Family Support Services
2911 E. Biddle Street
Baltimore, MD 21213

Sam Finz
Walcoff & Associates
635 Slaters Lane, Suite 400
Alexandria, VA 22314

Ray Ghahremani
Supplemental Food Programs Division
Food and Nutrition Service
U.S. Department of Agriculture
3101 Park Center Drive, Room 530
Alexandria, VA 22302

Frankie Gibson
Head Start Bureau
P.O. Box 1182
Washington, DC 20013

Donna Hines
Supplemental Food Programs Division
Food and Nutrition Service
U.S. Department of Agriculture
3101 Park Center Drive, Room 540
Alexandria, VA 22302

Roger Iron Cloud
Head Start Bureau
P.O. Box 1182
Washington, DC 20013

Arlene Kiely
Association for the Care of Children's Health
National Center for Family-Centered Care
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814

Jean Klinge
U.S. Department of Education
FOB 6, Room 2043
400 Maryland Avenue, SW
Washington, DC 20202

Donna Leno
Indian Health Service
Health Education Section
Parklawn Building, Room 6A-20
Rockville, MD 20857

Andrea Wargo, Ph.D.
U.S. Public Health Service
Hubert H. Humphrey Building
Room 727E
200 Independence Avenue, SW
Washington, DC 20201

Juliane Becket
University of Iowa
4555 Westchester Drive, NE
Cedar Rapids, IA 52402

Heather Block
Child Nutrition Service
U.S. Department of Agriculture
3101 Park Center Drive, Room 1007
Food Program Specialist
Alexandria, VA 22302

Adrienne Brigmon
Head Start Bureau
P.O. Box 1182
Washington, DC 20013

Sandra Carton
Head Start Bureau
P.O. Box 1182
Washington, DC 20013

Donna Rae Castillo
National Resources and Services Administration
Training Program
Division of Education, Evaluation, and
Demonstration
U.S. Public Health Service
U.S. Department of Health and Human Services
Parklawn Building, Room 18A-10
Rockville, MD 20857

Tony Fowler
U.S. Department of Education
FOB 6, Room 2155
Washington, DC 20202

Linda Jupin
Supplemental Food Programs Division
Food and Nutrition Service
U.S. Department of Agriculture
3101 Park Center Drive, Room 540
Alexandria, VA 22302

Marta Kealey

Supplemental Food Programs Division
Food and Nutrition Service
U.S. Department of Agriculture
3101 Park Center Drive, Room 540
Alexandria, VA 22302

Randy Kingsley

U.S. Department of Education
400 Maryland Avenue, SW
FOB 6, Room 2030
Washington, DC 20202

Patricia D. Mail

National Institute on Alcohol Abuse and Alcoholism
Faculty Development Program
Parklawn Building, Room 14C-20
5600 Fishers Lane
Rockville, MD 20857

Mary McGonigel

Associate Director, Association for the Care of
Children's Health
National Center for Family-Centered Care
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814

Latricia Robertson

U.S. Public Health Service
U.S. Department of Health and Human Services
Parklawn Building, Room 18A-55
5600 Fishers Lane
Rockville, MD 20857

Helen Scheirbeck

Head Start Bureau
P.O. Box 1182
Washington, DC 20013

Susan Wininger

U.S. Department of Education
400 Maryland Avenue, SW
FOB 6, Room 2033
Washington, DC 20202

Sharon E. Yandian

Head Start Bureau
P.O. Box 1182
Washington, DC 20013

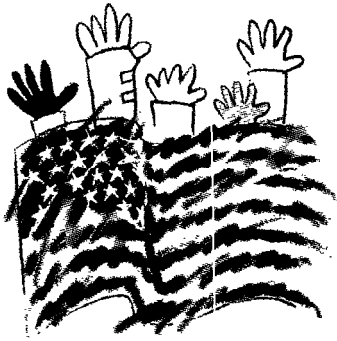
Workshops

Appendix F

Workshops

The Surgeon General's Conference

HEALTHY CHILDREN



Ready to Learn

The Critical Role of Parents

Washington, DC

February 9-12, 1992

Workshop 1

Eight Fatal Parent Paradigms and What You Can Do About Them

Bill Oliver

Executive Director

PRIDE Parent Training

Drugs are not new. However, parents' perspectives now about drugs are new. This workshop explored eight parental viewpoints that lead to adolescent involvement with the drug culture and described a model that can be used to shift these viewpoints.

Workshop 2

Caring for Your Infant and Young Child, AAP Publication

Steven P. Shelov, M.D.

Professor and Vice Chairman

Albert Einstein College of Medicine

Montefiore Medical Center

With the AAP's childcare book as an example, this workshop demonstrated to parents how to use the childcare information found in a parent guide to promote the health and well-being of their children.

Workshop 3

Department of Education Resource Room

The Education Resource Room allowed Conference participants to obtain more information on relevant programs administered by the U.S. Department of Education. Printed materials were available, and program officers were on hand to explain how each program works, how to **apply for** funding, and other important information.

Workshop 4

Migrant Education: Integration of Services

Patrick F. Hogan
Education Program Specialist
Office of Migrant Education
U.S. Department of Education

This workshop shared information about the Office of Migrant Education's coordination efforts among various programs and with other identified agencies that offer services to the Migrant population.

Workshop 5

An Introduction to the Head Start-Public School Transition Demonstration: The Importance of Parents

Michele Ann Plutro, Ed.D.
Education Specialist
Head Start Bureau

The workshop briefly **outlined** the Head Start transition demonstration and the key components required for its implementation in 1992, 1993, and 1994. The involvement of parents and families within the transition project was discussed.

Workshop 6

Head Start Initiatives for Parents: The National Parent and Child Centers' Program and the Comprehensive Child Development Program

Richard H. Johnson
Chief, Social Services, Parent Involvement, Parent-Child Centers' Branch
Head Start Bureau

Allen N. Smith
Special Assistant, Associate Commissioner
Head Start Bureau

This workshop presented two national special demonstration programs that are administered by the Head

Start Bureau and focused on providing services to income-eligible families with children younger than Head Start age. Both programs emphasize approaches and strategies that support the role of parents.

Workshop 7

Preventing Injuries to Children: What, Why, and How

Modena E. H. Wilson, M.D., M.P.H.
Associate Professor of Pediatrics
Johns Hopkins University

In this workshop, the most important causes of injury in early childhood were outlined. High risk groups were identified, and developmental issues were discussed. Prevention strategies and their implementation were presented. Supporting materials were provided.

Workshop 8

Public Health Issues in Child Daycare

Stephen B. Thacker, M.D., M.Sc.
Director
Epidemiology Program Office
Centers for Disease Control

This workshop focused on the public health issues related to children in daycare. Issues included the prevention of infectious diseases and injuries, the potential benefits of child daycare (especially with regard to child development), issues regarding children with special needs, and occupational health issues.

Workshop 9

Violence in Childhood: Where Does It Come From and What Can We Do About It?

Mark L. Rosenberg, M.D., M.P.P.
Director, Division of Injury Control
National Center for Environmental Health and Injury
Control
Centers for Disease Control

This workshop examined the problem of violence in America and focused on (1) the magnitude of the problem, (2) the impact of violence on children, (3) the public health approach to violence prevention, and (4) potential interventions and strategies for prevention.

Workshop 10

Immunization Coalitions: Mobilizing Communities to Increase Access to Care

Deborah Clark
National Field Director
National Immunization Campaign

This workshop related the experiences of the National Immunization Campaign that united the efforts of more than 25 national organizations and 7.5 community-based coalitions to demonstrate ways that diverse coalitions can broaden public access immunization and other primary care services.

Workshop 11

Parent Action: Finally! An Organization for ALL Parents

Rosalie Streett, M.S.
Executive Director
Parent Action

This workshop focused on why Parent Action, the only national membership organization for all parents, was established, what its goals are, what it does, and how

parents can get involved. Discussions centered on family issues and ways to help parents empower themselves to support our country's goal of strong, nurturing families.

Workshop 12

Enhancing Readiness to Learn: Mental Health and Social Competence in Early Childhood

Sandra J. McElhaney, M.A.
Director of Prevention
National Mental Health Association

Maurice J. Elias, Ph.D.
Associate Professor of Psychology
Rutgers University

The National Mental Health Association has long recognized the role of social competence in enhancing children's readiness to learn and to prepare for their roles as productive citizens. This workshop reviewed National Mental Health Association efforts in this area and outlined the best practices in early childhood programs.

Workshop 13

New Information for Parents about Nutrition for Young Children

Helen D. Lilly, Ph.D.
Food and Nutrition Service
U.S. Department of Agriculture

This workshop addressed what parents need to know about good mealtime experiences for the toddler and how to implement the new U.S. Dietary Guidelines in the diets of children older than two.

Workshop 14

Health Care for Children Living in Poverty

Charles P. LaVallee

Executive Director

Western Pennsylvania Caring Foundation, Inc.
Caring Program for Children

The Caring Program for Children provides free primary health care coverage to children who live in poverty but are ineligible for Medicaid. The workshop examined the impact of this innovative public-private partnership, which is now operational in 15 States. The Caring Program's new initiative, care coordination for children with special health care needs, was also presented. Plans for national replication were highlighted.

Workshop 15

Our Children Are Dying-What Are You Gonna Do?

Beverly Coleman-Miier, M.D.

President

The BCM Group, Inc.

This interactive workshop offered parents and others ways to control an apparently uncontrollable problem—violence and its impact on our children. Specific, proven initiatives were presented, along with the newest ideas from the leaders in the field. The roles of the community and the schools were discussed.

Workshop 16

Improving Access to Care: Peer Support Groups for Low-Income Pregnant Women and New Parents

Judith Rosenberg, L.C.S.W.

Director

Support Group Training Project

Both service providers and policymakers now acknowledge the need to address nonmedical social and psychological barriers that block access to care and preclude

improvement in the health of low-income populations and promotion of positive health practices. The Support Group Training Project organizes and facilitates peer support groups that are an effective way of delivering health education to low-income and minority pregnant women and new mothers.

Workshop 17

Poverty, Illness, and Child Development: A Pediatrician's Perspective

Steven Parker, M.D.

Director, Developmental Assessment Clinic
Boston City Hospital

This workshop focused on the double jeopardy of children growing up in poverty: (1) the increased risks for exposure to medical illnesses, substance abuse, and family disorganization and (2) the deleterious effects of these risks on children's ability to learn. Strategies about how to meet these children's needs were discussed.

Workshop 18

U.S. Department of Education Resource Room

The Education Resource Room was available for Conference participants to obtain more information on relevant programs that are administered by the Department of Education. Printed materials were available, and program officers were on hand to explain how each program works, how to apply for funding, and other important information.

Workshop 19

Parent/School Partnerships: A Chapter I Strategy for Improving Student Achievement

Diane D'Angelo
Research Associate
RMC Research Corporation

Chapter I programs have long advocated the involvement of parents in their children's education. This workshop provided participants with an overview of Chapter I programs, requirements for parent involvement, strategies to involve parents, and suggestions for home-based activities parents can use to support their children's education.

Workshop 20

"As I Am": An Early Childhood Mental Health Curriculum

Kirsten Hansen, M.Ed.
Director, Head Start Mental Health Project
Georgetown University Child Development Center

Promoting good mental health practices is important for all children. This workshop introduced the concepts of mental health, related methods of incorporating the curriculum into daily life, and presented lesson plans.

Workshop 21

Preventable Developmental Disabilities

Godfrey Oakley, M.D.
Division of Birth Defects and Developmental Disabilities
Centers for Disease Control

This workshop focused on major opportunities to prevent poverty-associated disabilities including mental retardation, spina bifida, and fetal alcohol syndrome.

Workshop 22

Childhood Lead Poisoning Prevention in the 1990s

Susan Binder, M.D.
Chief, Lead Poisoning Prevention Branch
Centers for Disease Control

This workshop focused on the Centers for Disease Control statement Preventing Lead Poisoning in Young Children. It presented simple ways to reduce lead exposure, and the shift to primary prevention of lead poisoning was discussed. The workshop also examined the roles of the following groups in preventing lead poisoning: Federal, State, and local agencies; legislative bodies; advocacy groups; private foundations; and individuals.

Workshop 23

Bright Smiles, Bright Futures: A Multicultural Approach to Oral Health Education

Alice M. Horowitz, M.A. (Moderator)
National Institute of Dental Research
National Institutes of Health

Marsha E. Butler, D.D.S.
Colgate-Palmolive Company

Robert S. Gold, Dr.P.H., Ph.D.
University of Maryland

Janice M. Hamilton, MS.
JMH Communications

Through a partnership with national Head Start and the University of Maryland, Colgate has developed a multicultural oral health education curriculum with interactive activities and support materials for pre-school and first grade children. Its specific aims are to (1) improve children's oral health knowledge, (2) improve children's attitudes toward preventive oral health care, (3) positively influence children's oral health behavior, and (4) encourage family involvement in children's oral health.

Workshop 24

Parents as Teachers: Ensuring Good Beginnings for Children

Mildred M. Winter, M.Ed.

Executive Director

Parents as Teachers National Center

This workshop centered on parents' role as the first and most influential teachers of their children and on a home-school partnership that supports parents of children from birth to age three in this role. Results from evaluations of the program's effectiveness were presented. Adaptations for teen parents, the childcare center, the workplace, and other program settings were described.

Workshop 25

Feeding Hungry Children

Barbara Hallman

Chief, Policy Branch, WIC Division

Food and Nutrition Service

U.S. Department of Agriculture

This workshop provided a description of the range and scope of food assistance programs available to Americans, with special focus on those serving very young (preschool) children.

Workshop 26

Tackling Children's Health in an Urban Center: One Corporation's Model Initiative

Nancy Van Doren

President

The Travelers Companies Foundation

This workshop detailed the involvement of The Travelers in community-wide efforts to improve children's health in Hartford, Connecticut. The model focuses on

collaboration and coordination of community resources and services. This model may be replicable in other communities.

Workshop 27

National SAFE KIDS Campaign-Preventing the Number One Killer of Kids: Childhood Injury

Herta B. Feely, B.A.

Executive Director

National SAFE KIDS Campaign

Childhood injury is the leading threat to the health of America's children. The National SAFE KIDS Campaign illustrates how community-based childhood injury prevention activities (in the areas of traffic injury, burns, falls, poisonings, chokings, and drownings) can be effective in reducing this threat. The workshop informed participants about the Campaign's resources and how to become involved in local SAFE KIDS initiatives such as Project GET ALARMED, SAFE KIDS BUCKLE UP, and the SAFE KIDS Bicycle Helmet Campaign.

Workshop 28

Capacity Building Through Early Intervention

Connie Garner, RNC, MSN, Ed.S.

Senior Program and Policy Specialist

Office of Special Education Programs

U.S. Department of Education

This workshop examined strategies for capacity-building for families with children with disabilities using the Part H conceptual framework. Links between health and education served as a fundamental building block of this discussion.

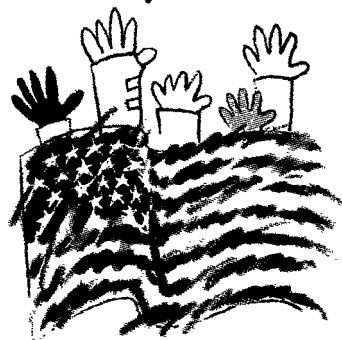
Exhibits

Appendix G

Exhibits

The Surgeon General's Conference

HEALTHY CHILDREN



--- Ready to Learn ---

The Critical Role of Parents

Washington, DC

February 9-12, 1992

Alliance To End Childhood Lead Poisoning
600 Pennsylvania Avenue, SE
Suite 100
Washington, DC 20003

America 2000
400 Maryland Avenue, SW
FOB 6
Washington, DC 20202

American Academy of Pediatric Dentistry
211 East Chicago Avenue, #1036
Chicago, IL 60611

American Academy of Pediatrics
141 Northwest Point Blvd.
P.O. Box 927
Elk Grove Village, IL 60009-0927

American Dental Association
211 E. Chicago Avenue
Chicago, IL 60611-2678

American Red Cross
431 18th Street
Washington, DC 20006

American School Food Service Association
1600 Duke Street, 7th Floor
Alexandria, VA 22314

Arkansas Department of Health
4815 West Markham Street
Slot 17
Little Rock, AR 72205-3867

Association for the Care of Children's **Health**
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814

Barbara Bush Foundation for **Family** Literacy
c/o Simon Schuster
15 Columbus Circle, 34th Floor
New York, NY 10023

Centers for Disease Control
1500 Clifton Road
Atlanta, GA 30333

Child Care Action Campaign
330 7th Avenue, 17th Floor
New York, NY 10001

Children's Hospice International
901 North Washington Street, #700
Alexandria, VA 22314

Department of Agriculture
Supplemental Food Programs Division
3101 Park Center Drive, Room 540
Alexandria, VA 22302

Elliot **Health** Systems/Elliot Hospital
80 Tarrytown Road
Manchester, NH 03103

Florida HRS State **Health** Office
1317 Winewood Boulevard
Tallahassee, FL 32399-0700

Health Care Financing Administration
200 Independence Avenue, SW
Washington, DC 20201

JMH Communications
c/o Colgate-Palmolive Company
300 Park Avenue
New York, NY 10011

Kids Adjusting Through Support, Inc.
600 East Avenue
Rochester, NY 14607

Maryland Department of **Health** and Mental Hygiene
201 W. Preston Street
Baltimore, MD 21201

MELD (formerly Minnesota Early Learning Design)
123 North Third Street Suite 507
Minneapolis, MN 55401

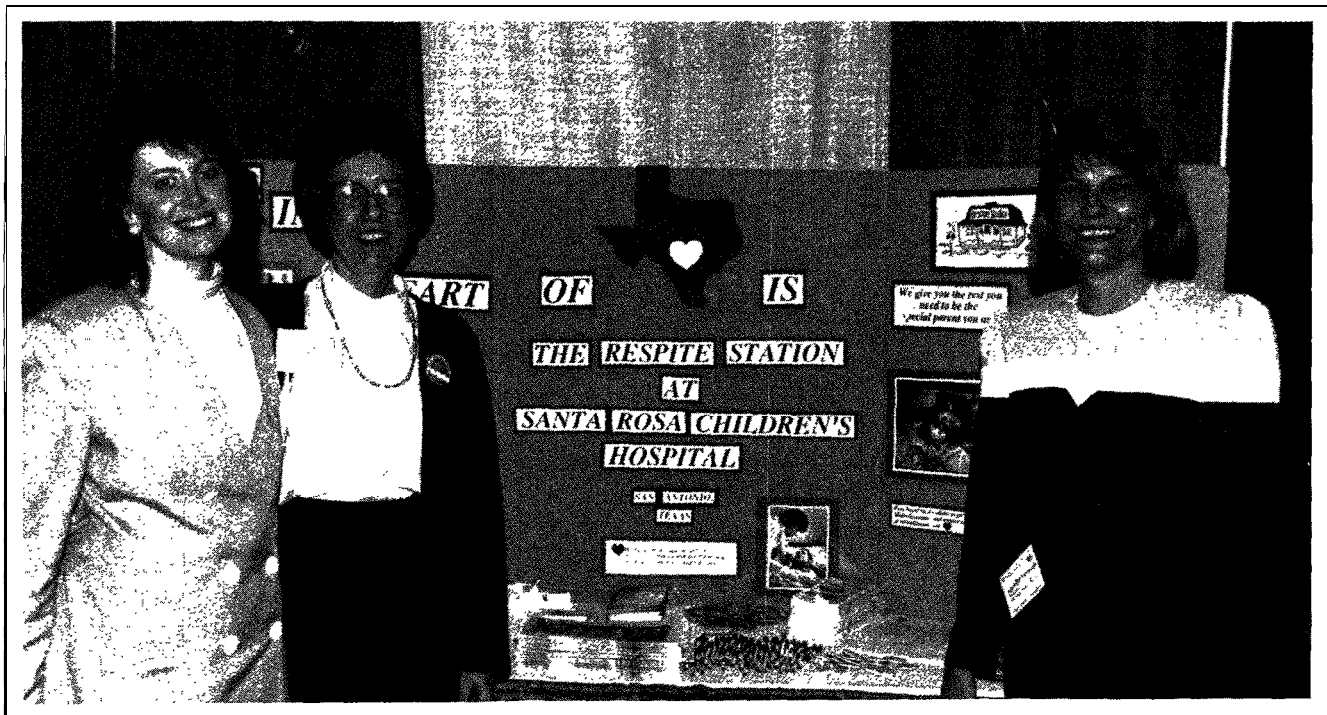
National Information Center for Children and **Youth**
with Disabilities
7926 Jones Branch Drive, Suite 1100
McLean, VA 22102

National Association of **Community Health** Centers, Inc.
1330 New Hampshire Avenue, NW
Washington, DC 20036

National Association of Elementary School Principals
1615 Duke Street
Alexandria, VA 22314

National Association of WIC Directors
P.O. Box 53405
Washington, DC 20009-3405

National Center for Clinical Infants Program
2000 14th Street, North
Suite 380
Arlington, VA 22201-2500



**National Center for Education in Maternal
& Child Health**
38th & R Streets, NW
Washington, DC 20057

National Head Start Association
201 N. Union Street, Suite 320
Alexandria, VA 22314

National Health Education Consortium
Switzer Building, Room 2014
330 C Street, SW
Washington, DC 20201

National Institute for Dental Research
9000 Rockville Pike
Building 31, Room 2C35
Bethesda, MD 20892

National Mental Health Association
1021 Prince Street
Alexandria, VA 223142971

National SAFE KIDS Campaign
111 Michigan Avenue, NW
Washington, DC 20010

National Urban League
500 East 62nd Street
New York, NY 10021

Pathfinder Resources, Inc.
2324 University Avenue West
Suite 105
St. Paul, MN 55114

**Reginald S. Lonrie Center for Infants and Young
Children of Maryland and Virginia**
11710 Hunters Lane
Rockville, MD 20852

South Carolina Governor's Office
1205 Pendleton Street
Columbia, SC 29201

State of New Jersey
CN 364
Trenton, NJ 08625-0364

Texas Office of the Governor
Capitol Station
P.O. Box 12428
Austin, TX 78711

Texas Respite Resource Network
Santa Rosa Children's Hospital
P.O. Box 7330
San Antonio, TX 78207-3198

The Home and School Institute
1201 16th Street, NW
Washington, DC 20036

United Way of America
701 N. Fairfax Street
Alexandria, VA 22314

University of Vermont
Department of Social Work
Burlington, VT 05405

U.S. Naval Reserve-Campaign Dmg Free America
P.O. Box 44
Marblehead, MA 01945



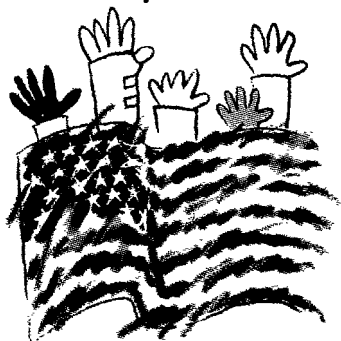
Entertainment

Appendix H

Entertainment

The Surgeon General's Conference

HEALTHY CHILDREN



--- Ready to Learn ---

The Critical Role of Parents

Washington, DC

February 9-12, 1992

We extend our thanks to the individuals and groups who provided entertainment during the Conference sessions and breaks. The performances reminded us, in many cases, of our country's varied cultural heritage. More importantly, the spark and vitality displayed by the children underscored the importance of the Healthy Children Ready To Learn Initiative and inspired us to work diligently to achieve our goal. Thank you to all who entertained and inspired us.

A handwritten signature in cursive script, reading "Antonia C. Novello".

Antonia C. Novello, M.D., M.P.H.
Surgeon General

Arlington County Head Start
Children Singers
Arlington Community Action
Program
Arlington, VA

Cathi Brown, Comedienne
Washington, DC

The Chicitas
Langley Park/McCormick
Elementary School
Hyattsville, MD

The Fabulous Flying Fingers
(chorus)
Barnsley Elementary School
Rockville, MD

Glenallan Chorus
Glenallan Elementary School
Silver Spring, MD

Joint Service Color Guard
Washington, DC

Kids on the Block
Columbia, MD

Keith Norris, Magician
Bowie, MD

North Springfield **Handbell**
Ringers
North Springfield Elementary
School
Springfield, VA

Rapping Cheerleaders
The Amidon School
Washington, DC

Singers West
West Potomac High School
Alexandria, VA

Town & Country Singers and
Ringers
The Newport School
Kensington, MD

Young Traditional Indian Singers
and Dancers
Indian Health Service
Baltimore-Washington Area





I ask you to join me to share the responsibility for making your family and your children well. Share with us at the local and at the State and at the National levels and in the public and the private sectors. It's no longer one person's responsibility. There is too much at stake!

Antonia C. Novello, M.D., M.P.H.
Surgeon General